TOWARDS DEMENTIA FRIENDLY EMERGENCY DEPARTMENTS

A mixed method, exploratory study identifying opportunities to improve the quality and safety of care for people with dementia in emergency departments

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Abstract

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Keywords: dementia, emergency medicine, patient safety, quality improvement, contributory factors, person centred care, nurses, doctors, carers, patients

Abstract:

This project provides the first comprehensive investigation into the experiences of people with dementia (PWD), their carers, and the staff who provide care in emergency departments (ED) in the UK. This is a mixed methods study which used a national survey (N=403) followed by ED observation (32 hours) and qualitative interviews with health professionals (N=29), in an iterative and sequential design to present a holistic evaluation of the current experiences of the key parties- patients, carers, and ED staff involved in receiving and providing care. The theoretical perspective of the Human Factors Approach to patient safety underpins this work. The project included people with dementia and carers as collaborators and co-designers in both the development of the research tools and in shaping the project outputs.

This research explores the barriers and facilitators to safe and effective care, concluding that here are a number of barriers (poor integration of communication systems, inappropriate physical environments, misalignment of staff training and workplace staffing models), which may affect the healthcare team's ability to provide effective dementia care. These systemic challenges both give rise to and exacerbate poor organisational and safety cultures. However, despite these challenges, there are examples of safe and effective care (positive deviants) where uncommonly good outcomes for this patient population are achieved. Examining these examples offers valuable insight into potential adaptions, which could be used to improve existing care.

Acknowledgements and dedication

I would like to acknowledge with gratitude the funding the from UK Alzheimer's Society which made the completion of this research possible. A generation of dementia researchers has benefited from your generous support. Additionally, I would like to thank the NHS organisations who hosted this research project and every participant who took the time to share their experiences with me. It has been an honour to work with you and I am eternally grateful for your contributions to this research.

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This thesis is dedicated in memory to my Grandma Joyce Shaw and my Grandpa Donald Brown who both lived with dementia.

Joyce Amy Shaw
January 9th1923- April 13th, 2017
I'll finally be the doctor you always wanted me to marry

Donald George Brown
April 25th, 1925- October 7th, 2017
Your loving, humorous presence made the world a more beautiful place

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Introduction

1.1 Aim of the study and research questions

The aim of this research is to develop a model of 'dementia friendly emergency departments within the context of the National Health Service (NHS) in the UK. The related research questions are:

1) What are the current experience of accessing care in emergency departments for people with dementia and their carers; specifically
    a. Are there are certain features of the admission pathway or experience of care in emergency departments that are considered problematic or especially positive?
    b. What is important to people with dementia and carers when they access care in an emergency department?
2) What are the current experiences of healthcare staff caring for people with dementia in emergency departments? In particular;
    a. What are the barriers to effective, safe care for people with dementia in the emergency department, and conversely, the facilitators of such care?
3) What structural and procedural changes would be required to enable provision of dementia friendly care in the emergency department in the NHS?

Throughout this thesis, the term emergency department is abbreviated to ED, and 'people', 'persons', or 'patients' living with dementia is abbreviated to PWD. The researcher recognises and acknowledges that the use of abbreviation when referring to a patient group is sometimes felt to be reductionist and not person centered. The use of abbreviation here is solely for the pragmatic purpose of reducing the overall word count.

Latest estimates from the Alzheimer's Society indicate that there are approximately 850,000 PWD in the UK, which is projected to rise to over 1 million by 2025 and over 2 million by 2051 (Alzheimer's Society, 2014). As there is a strong correlation between aging and risk of dementia, this increase in older people will have a significant societal impact as the incidence of dementia increases. Many PWD are also living with one or more co-morbidities, which makes them frequent, and generally appropriate, users of acute health services (Parke, Beaith, Slater, & Clarke, 2011). In the UK PWD account for 3.2 million bed days in acute care each year (Alzheimer's Society, 2016).

For many years, improving the quality of dementia care in the acute setting has been a governmental policy priority, and the movement to create dementia friendly hospitals has been championed since 2012 (Dementia Action Alliance, 2012). However, despite the considerable number of PWD entering hospital via the ED, the Dementia Friendly Hospitals initiative has focused primarily on ward based care. PWD are known to be particularly vulnerable and experience preventable harm more frequently than their peers throughout their time in hospitals. The cognitive impairment and communication difficulties, which are characteristic in most forms of dementia, mean PWD require additional support to mitigate against the increased levels of risk to which they are exposed. This is especially notable in the ED, which is considered hectic and disorientating for PWD. Adverse incidents in the ED can have serious impacts on the health and wellbeing of the patient throughout their stay, and in some cases can affect their ability to return home after a hospitalization. Poor care for PWD is estimated to cost approximately £264.2 million pounds each year (Alzheimer's Society, 2016). Therefore, improving the quality of care provided to PWD could represent a significant opportunity for cost savings in an increasingly cash-limited NHS.

1.2 Research design

As above, the aim of this study is to improve understanding of the current experiences of accessing care in ED to identify priority outcomes for PWD and their carers. These service-user priorities must then be balanced with the

practicalities of provision of urgent care in the ED setting. Therefore, it is essential to seek the input of healthcare staff providing care to identify facilitators and barriers to the provision of dementia friendly care in ED. With this in mind, the research was designed as a sequential, mixed methods project. Following a literature review, the project is divided into three empirical phases of work:

1) **Phase One:** A retrospective survey administered to carers and people living with dementia who accessed care in any ED in England within the prior 24 months.
2) **Phase Two:** A combination of observations, and structured interviews with a purposeful sample of 29 of health care staff; PWD and carers who attended the ED from two participating hospital sites.
3) **Phase Three:** A co-produced set of statements outlining the core features of dementia friendly emergency care, informed by the data from Phases one and two.

This study has been sequential and iterative. The survey data gathered in Phase One informed the direction of the interviews for Phase Two by highlighting current trends in experiences of care which merit further investigation. These trends were explored further in the in-depth interviews that formed Phase Two of the project. Patient safety research is a complex and multidisciplinary field, and a single method would be insufficient to fully explore the intricacies of the provision of safe care to this vulnerable patient group. The importance of exploring this issue from multiple perspectives and using multiple methods is reflected in the multi-stage, mixed-method research design.

1.3 Structure of the thesis

This thesis contains 11 chapters. This first chapter introduces the aims and research questions of the project and provides a guide for the rest of the thesis.

Due to the paucity of literature that is specific to safety of PWD in the ED it was necessary to divide the review of literature into two chapters. The second

chapter of this thesis is written as a narrative review and aims to provide a broad context of, and justification for, the importance of this research. The chapter discusses the current profile of dementia in the UK, including a discussion of epidemiology and policy. Furthermore, it will discuss key studies that address the issues of dementia in acute care, including exploration of patient and carer experience. Additionally, it will discuss some of the key patient safety issues which are relevant to PWD in acute care including; delirium, medication errors, falls, deconditioning, inappropriate medical intervention including use of anti-psychotics or invasive medical procures, and untreated pain. The majority of studies addressing these issues were undertaken in acute care settings outside of the ED, but the relevance and linkages to care in ED will be made explicit.

The third chapter is a systematic review of the literature published on the emerging topic of 'Geriatric ED's'. The literature is reviewed to identify key issues in geriatric emergency medicine, and the main features of geriatric services in ED including changes to the physical environment, implementation of technical procedures to improve quality of care, discussion of approaches to care, training programs and workforce models. This literature review further considers health and social outcomes that are attributed to the provision of geriatric, or senior friendly, ED's and identifies current gaps in the literature that this research can address.

The fourth chapter of the thesis discusses the methodological underpinnings for the study, providing a justification for the use of a critical realist approach and the use of mixed and multiple methods. This chapter also introduces the Human Factors Approach (HFA) as the underpinning patient safety theory that guides this project.

As this project uses both quantitative and qualitative methods, there are two methods chapters (chapter five: quantitative and chapter seven: qualitative) and two corresponding results chapters (chapter six: quantitative and chapter eight: qualitative). These chapters will discuss the methods used to collect data in each of the phases, and present the findings descriptively and analytically.

Following these four methods and results chapters, is an abbreviated chapter covering the co-design process which facilitated the creation of the “Dementia Friendly Emergency Department Statements”. Chapter ten is a fully integrated discussion chapter that explores the results in the light of available literature; this chapter also appraises the relevance of the findings for practice, policy and research, the limitations of this work, and proposes a series of key messages and recommendations. The final chapter of this thesis will provide a brief conclusion.

Throughout the thesis the structure, process, outcome (SPO) model (Donabedian, 2003) for quality improvement in healthcare is used as a framework to help organise data. This model was first proposed by Donabedian in 1966 and remains a dominant model for conceptualising healthcare improvement. The model is used to organise findings from the literature in the systematic review, was used as an a priori coding framework for free text in the surveys, and is used to structure the recommendations section. Ultimately, the decision to use the SPO model was influenced by its considerable history, prestige and acceptability within the discipline of quality improvement (Carayon & Wood, 2010).

Background

2.1 Introduction and purpose

This chapter provides background to the project and introduces the disease burden of dementia along with the socio-economic and policy context of dementia care. There is a brief discussion of the current challenges that face the health system, and a more detailed exploration of how an increase in the number of PWD interacts with existing systemic challenges. Additionally, this chapter will consider the experience and impact of hospitalisation from the perspective of the patient, and informal carer. Following this, there is a discussion of some of the key safety risks for PWD in hospitals and - where literature is available - how these risks manifest in the ED context. Finally this chapter introduces the concept of person-centered care, and explores why it is the preferred approach for PWD. It considers the tensions between the constantly evolving demands of emergency medicine and person centred approaches to care. Ultimately it presents the conclusion that while there may be challenges in implementation, the two concepts are not fundamentally incompatible. While the literature that forms this chapter was identified using systematic searching strategies in a series of mini scoping reviews, this chapter should not be regarded as a formal, critical review of the literature. Instead, it should be interpreted an introduction to the relevant facets of a much broader body of literature to orient the reader to relevant context.

The objectives of this chapter are

1) Explain the current social, economic, health system and policy context in which this thesis is grounded.
2) Introduce the literature that explores the current experience of older people in ED, and consider how these experiences are applicable to PWD. (This section also discusses the experiences of informal supporters or carers of PWD in ED.)
3) Explore the literature that discusses patient safety risk for PWD - both in the ED and in acute care more broadly.

4) Introduce the person centered care model, and discuss the inherent tensions between person centered care and task oriented ED systems.
5) Highlight current gaps in knowledge, and discuss how this project will make an original contribution in the field.

2.2 Social, economic, and policy context

As the population of the UK ages we are seeing shifts in the trends of hospital use (National Audit Office, 2018). When the NHS was first established it primarily treated patients for episodes of poor health brought on by communicable disease, or for a single health issue (Public Health England, 2017). As advancements in medicine and society have reduced the prevalence of communicable disease and improved our ability to treat conditions such as cancer or heart attack, the NHS is increasingly required to treat patients who have complex health care needs. Now patients who enter the hospital system with an acute complaint frequently have one or more chronic health conditions that also require management (Samaras, Chevalley, Samaras, & Gold, 2010). As the population ages, frailty and age related impairments in cognition and sensory inputs become more common, it is essential to ensure that healthcare staff are trained to provide holistic care, and to ensure that the health system is resourced and structured appropriately to provide care for patients with complex health needs.

2.2.1 What is dementia?

To understand why dementia is an increasingly important research issue, it is essential to define ‘dementia’. Dementia is an umbrella term that covers several different neurodegenerative conditions. Dementia has both biomedical and psychosocial impacts on the person who is affected and their wider personal network. The complexity of ‘dementia’ is described in the Prime Ministers Challenge Fund 2020 document (2015), which gives the following definition;

> "…'dementia' describes a set of symptoms that include loss of concentration and memory problems, mood and behaviour changes and problems with communicating and reasoning. These symptoms occur when the brain is damaged by certain diseases, such as Alzheimer's disease, a series of small strokes or other neurological conditions such as Parkinson's Disease. Around 60% of people with dementia have Alzheimer's disease, which is the most common type of dementia, around 20% have vascular dementia, which results from problems with the blood supply to the brain, and many people have a mixture of the two. There are other less commons forms of dementia- for example dementia with Lewy bodies and fronto-temporal dementia" (Department of Health, 2015, Pg 9)

The prevalence of dementia- especially Alzheimer's disease- is strongly associated with aging, and older people (aged 65+) make up an increasing proportion of the population. All epidemiological projections suggest that because of the link between aging and Alzheimer's disease, there will be an increase in the number of people living with dementia in the next 30 years. Therefore understanding dementia and ensuring the health service is able to cope with increasing demand, while providing care that is appropriate to the needs of people living with dementia, is essential.

2.2.2 Epidemiology

The latest estimates from the Alzheimer's Society indicate that there are approximately 850,000 people living with Dementia in the UK, which is projected to rise to over 1 million by 2025 and over 2 million by 2051 if age-specific prevalence remains stable, and increases are only driven by demographic ageing (Alzheimer's Society, 2014). This projection is contested, with researchers suggesting that improvements in public health and increased knowledge of preventative measures is likely to result in reductions in future prevalence (Ferri et al, 2005; Wu et al., 2016). Nevertheless, Age UK population projections indicate that by 2040, nearly one in four people in the UK will be aged 65 or over, and the number of people over 85 is projected to more than double (Age UK, 2015). As there a strong correlation between aging and risk of dementia- the likelihood of developing dementia roughly doubles every five

years- this demographic shift will have significant societal impact as incidence of dementia increases and more affected individuals require care within health and social care services.

2.2.3 Carer and societal impact

Associated with this increasingly aged population is an increase in the number of people who are providing care. A 'carer' is defined as;

> "Somebody who provides support or who looks after a family member, partner or friend who needs help because of their age, physical or mental illness, or disability. This would not usually include someone paid or employed to carry out that role, or someone who is a volunteer" (Department of Health, 2015).

Recent estimates suggest that there are approximately 540,000 people providing care in some capacity to a person with dementia in England (Department of Health, 2015). Estimates of the 'total contribution' of unpaid care in the UK range from £7.1 to £22.5 billion per annum depending on which economic calculations are used. The mostly widely accepted figured on the total contribution of unpaid care is £11.6 billion per annum (Alzheimer's Society, 2014). Part of this figure is the calculation of opportunity cost where carers have taken time out of paid work to provide support. It is estimated that around 50% of carers in the UK are currently in employment. In 2014 approximately 66,000 people had to reduce their working hours to enable them to undertake caring activities and around 50,000 people had to leave formal employment completely as a result of their caring responsibilities (Department of Health, 2015). An economic analysis of the costs of dementia to business found that the number of people having to leave employment is likely to increase to 83,100 in 2030 as 1 in 3 people will take on some form of caring role for a person with dementia in their lifetime (Alzheimer's Society, 2014; Centre for Economic and Business Research, 2014; Department of Health, 2015).

There are also significant implications for personal wellbeing associated with caring. Caregiver burden is the most frequent way of conceptualizing the

impact of dementia on a caregiver (Van Der Lee, Bakker, Duivenvoorden, & Dröes, 2014). This term encompasses both objective burden (i.e. the time spent on caring) and subjective burden (a complex and multidimensional construct relating to the social, psychological, and physical wellbeing of the carer). Carers of people with dementia frequently report poor mental health, high levels of stress and anxiety, social isolation, and loneliness as a consequence of their caring role (Department of Health, 2015; Douglas-Dunbar & Gardiner, 2007; Jurgens et al., 2012; Van Der Lee et al., 2014). A survey in 2017 by Carers UK showed that 50% of carers in the UK expected their quality of life to decrease in the coming 12 months, and only 10% were confident that the support they receive and rely on would continue (Carers UK, 2017). As more people take on caring roles to support individuals living with dementia, society and health systems leaders must be mindful of the impact the caring can have on the emotional and physical wellbeing of those providing care and ensure there are sufficient resources to support them in their role.

2.3 Economic and policy context

The costs associated with dementia care are an estimated £26 billion a year, which is more than heart disease, cancer or stroke (Department of Health, 2015). A significant portion of these costs is related to the provision of health and social care for people living with dementia. At the moment, the NHS is operating in an environment of austerity where the dual priorities of improving care and increasing efficiency have been prioritized as a means of making up for shortfalls in funding (NHS England, 2014)

The UK government's White Paper of 2010- *Liberating the NHS*- and subsequent *Health and Social Care Act* in 2012 represent the largest reform and restructuring of the NHS in its 70-year history. These changes included extensive restructuring to the way health services are planned, commissioned, and delivered. The reforms were championed as a means to reduce bureaucratic inefficiencies, refocus funding towards hiring of frontline staff, improve integration of care across providers, and improve patient outcomes. The structural reforms have occurred alongside austerity measures that have

had a significant impact on the funding of the NHS. In 2012, a report by the Nuffield trust predicted a funding gap of between £44-54 billion pounds by 2021/2022 based on the assumption of NHS funding being held flat in real terms beyond 2015 (Roberts, Marshall, & Charlesworth, 2012). This Nuffield Trust report stressed the importance of introducing wider efficiency reforms- particularly in acute care- to cover the majority of that projected shortfall.

Improving dementia care in the acute setting has been identified on multiple occasions as an opportunity for cost savings and as a service that requires improvement. In the UK, people living with dementia account for 3.2 million bed days in acute care each year, and recent estimates suggest that at a minimum, 25% of acute care beds are occupied by someone with dementia- though some suggest this figure could be up to 50% in some hospitals (Alzheimer's Society, 2016). Therefore, improving the quality of care provided to patients with dementia could represent a significant opportunity for cost saving.

In 2006, the Royal College of Psychiatrists recommended an audit of the care of people with dementia in general hospitals as a result of their assessments of improvement priorities. This was followed by a report from the Alzheimer's Society in 2009- *Counting the Costs*- that reiterated the need to improve the quality of care in hospitals for people with dementia. The National Dementia Strategy that was launched in 2009 also highlighted improving the quality of care in general hospitals as a key objective. The Dementia Action Alliance launched their campaign for *Dementia Friendly Hospitals* in 2012 that laid out five priority areas for improving hospital care. In 2013, a mandatory Commissioning for Quality and Innovation (CQUIN) was launched regarding the identification of dementia in hospitals, which dramatically increased the number of patients who were assessed and referred to memory services for diagnosis. However, this CQUIN did not have a notable impact on the standards of care provided, arguably because memory services did not offer effective post diagnostic support.

The issue was highlighted as a priority once again in the *Prime Ministers Challenge on Dementia 2020* published in 2015, and is the focus of an

Alzheimer's Society campaign- *Fix Dementia Care*- that was launched in 2016. A national audit of dementia care in acute hospitals was commissioned in 2016 and again reiterated the finding that dementia care in the acute setting requires improvement. This demonstrates a clear and consistent recognition of the importance of improving hospital care at a policy and strategic level; however, changes in practice have been slower to follow.

Many of the excess costs associated with dementia care in the acute setting are related to poor outcomes which people with dementia experience more frequently than their age matched peers without dementia. Research has shown that people living with dementia tend to stay in hospital longer, have worse medical outcomes, and experience poor care more frequently (Alzheimer's society, 2009; Alzheimer's Society, 2016; Holmes & House, 2000; King, Jones, & Brand, 2006; Sampson et al., 2009; Saravay et al., 2004). Poor inpatient care for patients with dementia- measured by the Alzheimer's Society as incidence of complications from avoidable falls, extended stays or delayed discharge, and emergency readmissions within a month- cost the UK approximately £264.2 million pounds each year (Alzheimer's Society, 2016).

Health Education England (HEE) uses a three tiered system to differentiate levels of dementia training among the health workforce; Tier 1- awareness that everyone should have, tier 2- basic skills which are relevant to staff in settings where people with dementia may appear, and Tier 3- Leadership (Health Education England, 2015). Dementia training can occur as part of higher education or on the job. A recent systematic review on dementia training and education reports there is a great deal of variability in the quality and content of training programs, and expresses a concern that government targets on 'number of staff trained' has lead to a focus on quantity, rather than quality education (Surr et al., 2017). Additionally, this review highlights a concern that theoretical and knowledge based training in an educational setting may not translate to effective real world practice- especially in a time and resource constrained system that is task oriented (Surr et al., 2017).

In conclusion, people living with dementia are frequent users of acute health services and while dementia is rarely the primary reason for admission (Sampson et al., 2009) the presence of dementia has a direct impact on the experience of accessing hospital care. The specific care needs of a person with dementia are unlikely to be met by standard provision of care (Alzheimer's Society, 2016) and thus there is a need to adapt and improve dementia care in the acute setting, including provision of better training for staff. These adaptations and improvements would offer an opportunity for cost savings, as well as a chance to improve experiences of care.

2.4 Patient experiences in the emergency department

As noted above, older adults frequently live with one or more co-morbid health conditions, and this makes them frequent users of acute health services (Parke et al., 2011). Several studies have demonstrated that ED patterns of use for older people are different to younger patients, but their usage is generally medically appropriate (Aminzadeh& Dalziel, 2002; Carpenter et al., 2014; Hwang & Morrison, 2016). In particular, research has shown that older people tend to arrive in ED more acutely ill, take longer to triage and diagnose, have more interventions and tests done, and are more frequently admitted into the hospital (Carpenter et al., 2014; Hwang & Morrison, 2016; Salvi et al., 2007). This is explained in part by the increasingly complex nature of geriatric care. ED's are designed to rapidly triage, diagnose, and treat a single acute complaint and this model is fundamentally misaligned with the care needs of older patients (Hwang & Morrison, 2016). In particular, older patients present a challenge to ED staff as they may demonstrate atypical presentation of disease, present with multiple comorbidities, and this may be complicated by poly-pharmacy. In addition, the care of older patients is more likely to be complicated by cognitive impairments such as dementia or delirium, and communication barriers due to sensory impairments (Carpenter et al., 2014; Hwang & Morrison, 2016; Kelley et al., 2010; Salvi et al., 2007). As a result, older people are more likely to have an extended stay in the ED (Émond et al., 2017) and are more likely to have a poor outcome following their ED visits (Fogg et al., 2017). There

is a growing awareness that the current disease-oriented and episodic model of emergency care does not address the complex needs of older patients (Ellis et al., 2018).

Despite the increased level of care that many older patients require in ED, many older patients are dissatisfied with the care they receive in ED (Bridges, Flatley, & Meyer, 2010; Grief, 2003; Parke et al., 2011; Shankar, Bhatia, & Schuur, 2014). It is important to note that the dissatisfaction with care is rarely related to the medical interventions which are received, but rather are associated with the experiences of care (Bridges et al., 2010; Grief, 2003; Shankar et al., 2014b). In particular, older patients reported feelings of worthlessness, being unimportant, isolated, abandoned, and fearful in the ED setting. Bridges et al (2010) found this was particularly notable if the patient had impaired cognition or communication difficulties.

One explanation for this dissatisfaction is a failure of the ED system to meet the higher level needs of older patients (Bridges et al., 2010; Nydén, Petersson, & Nyström, 2003). Nyden et al (2003) explored the reasons older patients were dissatisfied with ED care and found that while basic needs- as defined by Maslow's hierarchy (1943) - were generally met, the higher level needs for identity, connection, and community were not. This is echoed by Bridges et al (2010) who found that the three priorities for older people and their carers are to create communities, maintain identity, and participate in shared decision making. The fast paced interactions and biomedical focused ED system is typically not a clinical setting where these higher level needs can be met. This can lead to a loss of dignity, identity, and personhood, which can have a profoundly negative impact on the older patient- and particularly the older patient who is already vulnerable as a result of cognitive impairment.

The key to improving patient experience, according to Bridges et al (2010) and Shankar et al (2014) is the provision of relationship-centered approaches to care. This approach enables a more holistic evaluation of the patient, better provision of supportive care, and facilitates more effective integration of formal (healthcare) and informal (family) care. The central element

of relationship-centered care is communication. Therefore, improving communication about prognosis, wait times, the anticipated course of action, and providing reassurance of the appropriateness of the patients attendance is key to reducing anxiety and supporting the older patient during their time in ED (Bridges et al., 2010; Nydén et al., 2003; Parke et al., 2013; Shankar et al., 2014).

2.5 Carer experiences of the emergency department

Many carers report the experience of taking older relatives to the hospital as a negative experience. A study conducted by Ridley (2012) and a systematic review of literature done by Bridges, Flatley, and Meyer (2010) found that carers who accompany relatives to the ED find the experience distressing and overwhelming. Both attribute this to the busy, unfamiliar, and largely bio-medically focused environment, which can leave carers feeling overwhelmed and disempowered. Similar explanations are offered by Laitinen & Isola, (1996), Allen (2000), Douglas-Dunbar & Gardiner (2007) Jurgens et al. (2012), Clissett et al. (2013), and Whittamore et al. (2014) who all report that carers describe significant challenges in supporting their relatives with dementia while in hospital. The literature also identifies contributory factors that may increase the challenges that carers face while trying to support their relatives. These include physical infirmity or psychological stress of the carer on admission (Jurgens et al., 2012; Whittamore et al., 2014), and psychological stress related to the acuity of illness experienced by the relative needing care (Bridges et al., 2010; Parke et al., 2013; Whittamore et al., 2014). It is interesting to note that several of these studies indicate the carers experience increased stress when the patient exhibits behaviours which may be perceived as ‘challenging’ or ‘disruptive’- such as shouting, wandering, or becoming non-compliant or combative with staff (Bridges et al, 2010; Whittamore et al, 2014). These behaviours may be the result of dementia, co-morbid delirium or distress (Whittamore et al., 2014). Bridges et al (2010), Parke et al. (2013) and Ridley (2012) also report that containing behaviors which are perceived as

challenging, adds psychological stress for carers who are already experiencing stress related to the health of their relative.

Of particular relevance to this research is postgraduate research done by Ridley (2012), a nurse from New Zealand, who submitted a thesis titled *Sidelined: Family Caregiver's Experience of the Emergency Department- Insights from family caregivers of people with Alzheimer's Disease* which focused specifically on the experiences of family caregivers in ED when the patient has dementia. A key theme which emerged in the phenomenological analysis was the dissatisfaction with level of involvement in care and support expressed by the participants- with some participants noting that they were expected to do to much, and other saying they were not permitted to be involved as much as they would like. This highlights the importance of communication to ensure appropriate levels of involvement are being sought from each individual carer. Interestingly, this point is evident in the literature on children's hospital care and family involvement, and is one of the key conclusions from a comprehensive analysis of the lived experience of parents in hospital (Darbyshire, 1994). The parallels between paediatric care and dementia care have been identified in the work of Howe (2015).

The challenges that carers face in supporting their older relatives in ED persist despite widespread acknowledgement by staff that family carers play an important role in improving the quality and safety of care (Borbasi et al., 2006). The importance of understanding and improving carers experience is highlighted by Bridges et al (2010) who notes that carers who are unfamiliar with medical language, intimidated or overwhelmed by the busy environment, or experiencing anxiety related to the medical condition of the patient, may find it challenging to communicate with the staff effectively. This subsequently limits their ability to act as an advocate or supporter for their relative.

2.6 Patient safety and dementia

As discussed in the introduction there is a limited empirical literature on patient safety risks for PWD specific to the ED setting. However, there are several audits (Alzheimer's Society, 2009; Alzheimer's Society, 2016; CHKS,

2013; Timmons et al., 2016; Tolson, Smith, & Knight, 1999) and reviews (Bridges et al., 2010; Dewing & Dijk, 2014; George, Long, & Vincent, 2013; Metsälä & Vaherkoski, 2014; Moyle et al., 2011; Samaras et al., 2010) which identify the safety risks for individuals with dementia in hospital. Additionally, there are some notable papers which discuss the operational environment of the ED and how this affects PWD (Clevenger et al.,2012; Hwang & Morrison, 2016; Parke et al., 2013; Parke et al., 2011; Parke & Chappell, 2010). By reviewing these papers it is possible to identify how the risks identified for patients with dementia are associated with the physical and operational structures of the ED. The following safety risks are explored below:

- Transitions in care,
- Communication based errors,
- Falls,
- Inappropriate or invasive interventions,
- Inadequate pain relief,
- Distressed behaviours and sedative use,
- Medication errors, and,
- Delirium.

2.6.1 Transitions in care

Transition points such as a move from a care home or community into acute care via the ED can be period of increased risk for PWD (Coleman, Chalmers, & Rosenbek, 2011). Transitions can be points of risk as changes in location or level of care require a transfer of responsibility and corresponding transfer of medical and biographical information (Carayon & Wood, 2010). This is particularly important when considering a transition from the community into the hospital as this represents a change in both level and location of care. The patient journey into the hospital- via ED- has multiple transition points each requiring a handover of care responsibility and information (Salinas & Ramakrishnan, 2012). Within the ED it is common for patients to move several times between areas of triage, diagnosis, treatment, and observation as well as

being cared for by up to three different shifts of staff in any 24-hour period (Coleman et al., 2011; Parke et al., 2013).

The importance of effective transfer of information at transition points has been widely acknowledged and a number of tools have been designed to facilitate the transfer of clinical information between healthcare staff- from paramedics to hospital staff or at shift change for example. These tools, including acronym-led checklist models such as SBAR (Situation, Background, Assessment, Recommendation) and ISOBAR (Introduction, Situation, Background, Assessment & Recommendation/discussion) are used to facilitate the effective transfer of information at points of transition, and are designed specifically to be fit for purpose in the busy ED environment (Owen, Hemmings, & Brown, 2009; Western Australia Country Health Service, 2009; Woodhall, Vertacnik, & McLaughlin, 2008). However, these tools are designed for, and used by, clinicians. To date there is limited academic evidence of similar facilitated communication tools being used to enable the transfer of information from informal carers (such as family and friends) to clinical staff.

The ED system is typically reliant on the patient being able to communicate their history, current condition and needs at each of those transition points. Therefore, PWD who may have impairments in their ability to communicate are exposed to risk as they may be reliant on others transferring information on their behalf. In most case these 'information guardians' are health professionals (i.e care home staff, GP's, or paramedics) or family carers. Information guardians acting in a professional capacity may be reliant on information written in notes that can be incomplete or out of date (Salinas & Ramakrishnan, 2012). Family carers who are acting as information guardians may find the ED overwhelming and stressful and therefore find it challenging to communicate or advocate effectively (Bridges et al., 2010; Ridley, 2012). Consequently, ED staff have not have access to accurate medical and biographical information as a result of these multiple transitions. These communication failures can cause serious breakdowns in the continuity of care, inappropriate treatment, and patient harm (Coleman, 2003).

2.6.2 Communication

Communication failures- either between clinical staff or between clinicians and patients- are a frequently cited contributory factor to patient safety incidents and episodes of poor care (Carayon et al., 2014; Carayon & Wood, 2010; Parry, 2011; Sutcliffe, Lewton, & Rosenthal, 2004; Woodhall et al., 2008). Dementia can affect both expressive and receptive communication ability, and this means caring for PWD may require adapted practices. Expressive communication is the ability to share thoughts and feelings in words and sentences or other means of interaction, and receptive communication is the ability to understand and process information that is presented by others. For PWD who may struggle to communicate their needs or understand information, it is essential to ensure there is effective three-way communication between the healthcare staff, the patient and- if present-the carer, to keep the patient safe.

The difficulties with expressive communication can lead to inaccuracies in medical or medication history, difficulty gathering information on current condition, or inability to express unmet psychosocial needs (Andrews & Christie, 2009; Parke et al., 2013; Tsilimingras, Rosen, & Berlowitz, 2003). The challenges with receptive communication can impact a patient's ability to understand information given to them by healthcare staff and may impair a patients ability to follow instructions. It is also important to note that communication is a two way process, and if staff are unsure or anxious about their ability to communicate with a PWD this may impact the safety of the patient. These issues of ineffective communication can increase a patient's risk of experiencing harm as they may not receive adequate information, or may become distressed if they cannot understand their environment and/or cannot follow instructions required for self-care or to ensure safety (Andrews & Christie, 2009; Parke et al., 2013; Tsilimingras et al., 2003). As dementia is a progressive disorder, at some point many PWD may experience some form of communication difficulty. This may be especially notable if they are affected by sensory impairment or a co-morbid condition that has an additional impact on cognition such as serious infection or delirium.

In many cases it is possible to enable effective communication with a PWD, but it requires an appropriate environment, additional time, adaptions that support the PWD, and a staff member who is trained to provide person centered care. In the ED staff balancing the needs of multiple patients with varying levels of acuity may find it difficult to create an environment that enables the PWD to communicate (Borbasi et al., 2006; Moyle et al., 2011). In some instances, when it is perceived to be 'too difficult' to engage with a PWD, staff may resort to speaking solely to a carer as it is perceived to be easier, faster, and more accurate (Bridges et al., 2010; May, Ellis-Hill, & Payne, 2001; Parke et al, 2013; Parke & Chappell, 2010). Whilst this approach may feel necessary to clinical staff it can make the patient feel unvalued and can increase the feelings of fear, worthlessness and loss of autonomy that some older patients report experiencing at the time of an admission (Bridges et al., 2010).

2.6.3 Falls

Reducing the number of falls while in hospital is a significant patient safety priority. Falls are associated with a number of adverse health outcomes including extended length of stay and moves to residential or nursing homes on discharge for older patients (George et al., 2013). PWD have an increased risk of falling while they are in the hospital (Alzheimer's Society, 2016; Comparative Knowledge Health System, 2013; Samaras et al., 2010). An analysis of hospital episode statistics by the Comparative Health Knowledge System- managed by Capita- (2013) using data from 2010-2011 found that PWD are three times as likely to experience a fall in hospital when compared to their peers. Hwang and Morrison (2016) argue that this risk is particularly high in the ED, which they attribute to the slippery flooring as well as the unfamiliar and sometimes crowded environment that increases the risk of tripping. They further note that certain patient characteristics- such as, delirium or confusion- can also increase the risk of falls and give an example of PWD trying to mobilize despite being advised not to, especially if they feel they cannot summon assistance or forget to use the call bell (Hwang & Morrison, 2016). This is supported by a small

study by Duffy et al (2005) which found that older adults in hospital may struggle to use call bells and as a result attempt to mobilize without adequate supports. Managing the risk of falls is an important consideration in creating a 'dementia friendly' ED as the risks of secondary harm caused by falls must be balanced against the increased risk of delirium and functional decline which can be aggravated by prolonged immobilization (George et al., 2013; Hwang & Morrison, 2016; Saravay et al., 2004).

Although length of stay in the ED should be relatively short, retrospective analysis of patient records (Ackroyd-Stolarz et al., 2011) and interviews with carers (Parke et al., 2013) show that older patients with complex needs can spend extended periods in the ED waiting for a bed to become available on an appropriate ward. Comprehensive assessment of falls risk is infrequently done in ED, but concern about the potential of falls may sometimes mean that PWD are confined to their beds for extended periods.

2.6.4 Inappropriate intervention

There is a body of evidence that suggests that PWD experience unnecessary, and sometimes invasive, medical procedures in the ED. The most frequently referenced procedure is the placement of indwelling urinary catheters without clear medical need. The use of indwelling catheters is strongly associated with an increased risk of 'infectious complications' from urinary tract infections (Ahmed, Leurent, & Sampson, 2014; Fakih et al., 2010) as well as non infectious complications such as pain, decreased patient mobility, and decline in patient function (George et al., 2013; Hwang & Morrison, 2016; Saint et al., 2018). Use of indwelling catheters is also a known risk factor for the development for delirium (Ahmed et al., 2014; George et al., 2013; Watkin et al., 2012). Finally, catheterization in hospital can have long- term impacts on a person's continence which may in turn have an impact on their ability to return to, or remain at home (Fakih et al., 2010).

A large (N=4521) retrospective examination of ED patient records carried out by Fakih et al. (2010) found that there was no clinical indication of

requirement for almost half of patients over 80 who had a catheter inserted in the ED. This was particularly notable for women over 80, who were 2.9 times more likely than younger women to have a catheter placed without indication. While this study was not specific to PWD it has important implications, as age is strongly associated with the presence of dementia. A large study (N=617) by Sampson et al. (2006) which retrospectively evaluated patient records to identify differences in care between PWD and those who are unaffected also found that the use of catheters and nasogastric tubes was significantly higher in PWD. Hwang and Morrison (2016) attribute this increased use of catheters in older patients in the ED to constraints on staff time that reduces ability to assist patients with toileting or change incontinence products. They further note that the use of catheters in this patient population may be an indicator of a risk-averse culture where catheterisation may be perceived as an effective means of reducing unsupervised mobilisation related to needing to use the toilet.

Sampson et al. (2006) also found that PWD were more likely to have nasogastric tubes inserted during their time in hospital, though the precise setting where these interventions took place is not clear. Additionally, they noted PWD had their blood gases measured more frequently- which they suggest may be a result of the increased risk of secondary infection and the patients perceived inability to communicate changes in symptoms, which can lead clinicians to being more reliant on clinical investigations. This is echoed in part through a comparative investigation of palliative care for PWD and those without in an Irish hospital (Afzal et al. 2010). This large, retrospective analysis of patient records found that while there was no statistically significant difference in frequency of invasive or potentially painful procedures between the two patient groups, the PWD were significantly less likely to receive pain relief before these procedures and as such may be subjected to excess suffering as a result.

These cases highlight some interesting trends in the pattern of treating PWD in acute care. The evidence supports the conclusion that PWD are treated differently while in the hospital, and this is likely to be reflected in the

care that is received in the ED. Unnecessary or invasive medical procedures may be carried out on PWD as it is perceived to be time saving, protective, or necessary to supplement possibly incomplete communication of physical condition. However, these procedures can have negative impacts as they can expose the patient to additional risks associated with secondary infection and excess discomfort.

2.6.5 Inadequate pain relief

Strongly associated with the concept of excess discomfort is the issue of pain relief. Several studies have demonstrated that PWD receive less pain medication than their peers without dementia who are admitted with similar complaints (Afzal et al., 2010; Jurgens et al., 2012; Parke et al, 2013; Sampson et al., 2006). Of particular interest for this research is the study done by Sampson et al (2006) which found that PWD who have a neck of femur fracture receive one third of the levels of analgesia prescribed for their peers who do not have a cognitive impairment (Sampson et al., 2006). Hip fracture is a frequent cause of attendance in ED's for PWD, and is known to be extremely painful for the patient. A descriptive paper by Achterberg et al.(2013) discusses some of the challenges associated with pain management for PWD. They argue the primary issue with provision of pain relief is that there is currently a poor understanding of how dementia affects an individual's perception of pain- in part because of the communication challenges that are associated with dementia. Additionally, this paper discusses the lack of high quality observational tools for assessment of pain in individuals with impaired ability to communicate, and notes that there is some confusion amongst medical professionals about the efficacy and appropriateness of using specific analgesics for patients with cognitive impairments. While these are importance considerations, it is also essential to understand the impact of untreated pain as it is widely recognized as a key contributory factor in the development of distressed behaviors, frequently referred to as behavioral and psychological symptoms or BPSD (Achterberg et al., 2013; Hwang & Morrison, 2016; Samaras et al., 2010;

Sampson et al., 2006; Cunningham & McWilliam, 2006). The development of these distressed behaviours is associated with carer stress (Jurgens et al., 2012; Whittamore et al., 2014) and also to the use of anti-psychotics or sedatives that can increase the risk of developing delirium.

2.6.6 Distressed behaviours, sedatives, and anti-psychotic use

There is a large body of evidence that indicates that the physical environment of an ED can be extremely distressing for a PWD, who may experience anxiety, agitation, or restless behaviour such as trying to walk around or leave (Clevenger et al., 2012; Cunningham & McWilliam, 2006; Hwang & Morrison, 2016; Parke et al., 2013) The systems that are used to assist in triaging and managing patient flow are not designed for geriatric patients, and because of this, the holistic needs of older patients are frequently unmet within this environment. Parke (2013) conducted a social ecological study of the facilitators and barriers to safe ED transitions for older adults with dementia, which used interviews with care dyads to identify structural issues and care practices which supported, or hindered, safe transitions into the ED. One of the key findings from this study was that the triaging processes are typically designed to prioritize biomedical conditions, and this can lead to diagnostic overshadowing; or PWD being under-triaged leading to long waits in the ED. This finding was similar to that of Hwang and Morrison (2016) who discussed the mismatch between the needs of older adults and the way care is organised and delivered in ED. Both papers discuss the weaknesses of triage, which is designed to be rapid and diagnostic, and explain how this may be inappropriate for older adults who have multiple comorbidities, poly-pharmacy, and functional and cognitive impairments that can manifest as nonstandard clinical symptoms and signs of acute illness. These inappropriate systems, can lead to extended stays in ED, which is a risk factor for development of delirium and can sometimes manifest as exhibition of distressed behaviours (Ackroyd-Stolarz et al., 2011; Saravay et al., 2004).

In writing about best practices for providing care in ED's for PWD both Andrews & Christie (2009) and Cunningham & McWilliam (2006) discuss the important role the physical environment of the ED plays in affecting patient behaviour- in particular in the development of behaviours which are perceived as challenging. These papers, written for clinicians by clinical academics, encourage staff caring for PWD to consider these distressed behaviours as manifestations of unmet needs in line with recommendations from the All-Party Parliamentary Group on Dementia (2013). In particular the papers by Andrews & Christie (2009) and Cunningham & McWilliam (2006) urge clinicians to consider the potential impact of untreated pain, dehydration, or delirium, as these are all potential triggers for behaviors that are challenging.

Unfortunately, despite these best practice guidelines which encourage holistic appraisal of patient conditions and non-pharmacologic solutions, the use of anti-psychotics and sedatives is still prevalent in the management of distressed behaviours amongst patients with dementia in acute care (Alzheimer's Society, 2009; Dewing & Dijk, 2014). The systematic review of literature done by Dewing and Dikj on the current state of care for PWD in general hospitals (2014) found that doctors frequently prescribe sedatives and anti-psychotics as a first line of treatment for the management of behaviors that challenge rather than pre-empting distressed behaviours or attempting psychosocial intervention. In this review Dewing and Dikj cite literature that suggests this is a result of nurses requesting the prescriptions to calm patients, as they do not feel able to manage the behaviors. This is supported by research funded by the Alzheimer's Society (2009), Moyle et al. (2011) and Borbasi et al. (2006) which identify managing behaviors that challenge- such as wandering, vocalizing, aggression, becoming non-compliant with treatment, or restlessness- as one of the most challenging aspects of nursing PWD (Alzheimer's Society, 2009). Anti-psychotic use has been linked to increased risk of stroke, falls-including serious falls causing fractures, cognitive decline, deep vein thrombosis, and increase risk of mortality (Azermai, 2015). Banerjee (2009) concluded that there is limited evidence suggesting effectiveness in

using antipsychotics to addressing behavioral disturbances, and noted that despite the lack of efficacy, use of antipsychotics is linked to a significant increase in absolute mortality risk.

2.6.7 Medication errors

Older patients have the highest risk of experiencing a patient safety event while they are in hospital- including high risk of medication errors (Ajdukovic et al., 2007; Dormann et al., 2013; Tsilimingras et al., 2003). This includes errors of omission, such as missed doses of routine medication taken to manage chronic conditions, (Tsilimingras et al., 2003) as well as more serious adverse events related to medication allergies or medication interactions caused by poly-pharmacy (Ahmed et al., 2014; Samaras et al., 2010; Tsilimingras et al., 2003; Watkin et al., 2012).

One explanation for this increased risk is the prevalence of poly-pharmacy within this patient group (Ajdukovic et al., 2007). Shah and Hajjar (2012) report that poly-pharmacy- defined as taking between two and seven drugs daily- increases the risk of an adverse drug event, and older patients- particularly those who live in residential care, where up to 60% have dementia or other cognitive impairment (Matthews & Dening, 2002)- are most likely to be taking multiple medications (Ajdukovic et al., 2007). Shah and Hajjar (2012) note that 13% of people taking two drugs will experience an adverse drugs event in hospital, and this rises to 58% for those taking five drugs, and 82% for those taking seven or more medications. Another possible explanation for the increased risk is a failure to reconcile medications at points of transition- such as admission to hospital via ED. A study done by McCullagh, O'Kelly, & Gilligan (2015) found that only 51% of GP referral letters to ED documented a comprehensive medications list which included dosage and frequency. Furthermore, they found only 14% of letters included information about drug allergies. Concurrent to this finding is evidence that medication adherence is negatively related to poly-pharmacy- with higher rates of non-adherence as the number of medications increase (McCullagh et al., 2015; Shah & Hajjar, 2012).

McCullagh, O'Kelly, & Gilligan (2015) found only 22% of older patients taking medications as prescribed by the doctor and Shah and Hajjar reported on studies which demonstrated adherence rates between 43-95% depending on how adherence was measured.

It is clear that older adults have a higher risk of adverse events related to medication errors, and PWD experience even higher risk than their age matched peers. The challenges with memory and communication described above increase the risk that the patient will have an adverse event as they may be unable to share an accurate medical history or complete medications list. This in turn increases the risk that the patient may experience an adverse drug interaction, or miss regular doses of routine medications.

2.6.8 Delirium

Delirium is an acute confusional state that is typically associated with periods of ill health. It is common, with 10-31% of patients showing signs of delirium on admission to hospital, and is particularly notable in PWD (Ahmed et al., 2014). It is estimated that between 66%–89% of PWD will develop delirium while they are in the hospital, and they are 30 times more likely to develop delirium than age matched peers without dementia (Ahmed et al., 2014; Fong et al., 2009; , Inouye, & Jones, 2017; Whittamore et al., 2014). With good preventative and clinical care, delirium can be prevented in up to one third of cases (Ahmed et al., 2014). Development of delirium has been linked to increased length of hospital stay, diminished physical functioning, higher mortality, increased carer distress and poor experience of care (Ahmed et al., 2014; Bridges et al., 2010; Fong et al., 2009; Fong et al., 2017; Hwang & Morrison, 2016; Ridley, 2012; Whittamore et al., 2014)

There has been a recent increase in interest around the relationship between dementia and delirium as new evidence suggests that it is more complex than originally thought. New research by Fong et al (2017) has demonstrated that episodes of delirium in hospital can increase the speed of cognitive decline in dementia. This insight is the result of a large, quantitative

investigation of long- term outcomes comparing PWD who experience delirium and those who did not. Notably, extended time in the confusing environment of an ED has been identified as a key risk factor for the development of delirium (Hwang & Morrison, 2016). Preventing the development of iatrogenic delirium is therefore important for the safety of patient while they are in the hospital (Fong et al., 2017).

2.7 Person Centered Care, Dementia, and Emergency departments

Person centred care is a frequently used, but often poorly defined, philosophy of care that stresses the importance of understanding personal circumstance and experience to tailor medical intervention and psychosocial support to the individual (Tee & Andrew, 2016). In the context of emergency medicine, McConnell, McCance and Melby (2016) define person centeredness as "*a standard of care that places the person at the centre of it- moving away from fragmented, medically dominated care towards care that is relationship focused, holistic, and collaborative*" (Pg 39). A core belief within the person centered philosophy is that the improvement of patient experience is related to being cared for with kindness, compassion, and respect for one's personhood as much as it is with improving good clinical practice (Goodrich & Cornwell, 2008). Person centred care is considered an alternative to traditionally 'task based' medicine in the ED, and has been increasingly promoted in the last decade as a approach to enhancing quality of care in both national and international health policy and strategies (McConnell et al., 2016)

In particular, person centered approaches to care have been championed as best practice for individuals living with dementia. Guidance from the National Institute for Health and Clinical Excellence states "*the principles of person-centred care underpin good practice in dementia care*" and instruct acute care trusts in the NHS to provide training for their staff in person-centred and outcome-focused care for PWD (National Institute for Health and Care Excellence, 2018). The value of person centred care was also re-enforced in the National Dementia Strategy (Department of Health, 2009), the Prime Ministers Challenge on Dementia 2020 (Department of Health, 2015) and the

Alzheimer's Society call to improve dementia care in acute care settings (Alzheimer's Society, 2016).

In addition to improving the experience of care through more dignified and equitable interactions with staff, it can be argued that person centred approaches to care might also improve quality and safety of care for older people. As a result of the more holistic and relationship focused approach of person centred care, the complex medical and social needs of older patients with cognitive impairments or other comorbid conditions are more effectively identified and addressed (Melady & Perry, 2018). This may enable earlier recognition of potential safety risks and could potentially prevent the cascade iatrogenesis associated with hospitalisation which is described in literature on older peoples experiences of acute care (Aldeen et al., 2014; Andrews & Christie, 2009; Banerjee, Conroy, & Cooke, 2013; Burton, Young, & Bernier, 2014; Clevenger et al., 2012; Hwang et al., 2013; McClelland & Sorrell, 2015; Perry, Tejada, & Melady, 2018).

However, despite person centred care being championed as best practice for PWD and older adults with complex health care needs, there are some who believe person centred approaches to care are fundamentally incompatible with the demands of emergency medicine. Sceptics sometimes believe the dynamic, needs driven environment of the ED which is dominated by medico-technical demands make person centred care an unachievable goal (McConnell et al., 2016). There are arguments that seem to support this theory including; ED staff feeling person centered care is not a priority, and a socio-environmental context that prioritizes efficiency and medical care. For example, ED nursing staff have reported that they view their skills as predominantly medical- i.e. keeping the patient alive- and technical- i.e. maintaining patient flow through the department- rather than viewing provision of holistic care as a core element of ED nursing (Elmqvist, Fridlund, & Ekebergh, 2012; McConnell et al., 2016; Nyström, Dahlberg, & Carlsson, 2003; Skar et al., 2015). It is suggested by McConnell et al (2016) that this is a means of self-protection to prevent emotional burnout that could come from forming attachments with

patients who largely transition through the department rapidly. Unfortunately, this 'self preservation' mechanism has embedded itself into the culture of ED medicine and contributed to a model of care where biomedical care is prioritized- sometimes at the expense of holistic care (McCormack, Dewing, & McCance, 2011).

Additionally, in the UK, healthcare staff are providing care in the context of bureaucratic demands on efficiency in the form of four hour targets (Munir, 2008). Munir (2008) reported that older patients frequently reported feeling rushed and unable to fully explain their challenges or personal circumstances in ED due to time constraints. These efficiency targets were designed to improve patient care, but may be having the opposite effect for older people whose complex needs and requirements for holistic assessment or intervention cannot be met within the time constraints. Lastly, it is important to be mindful of the impact that the physical environment has on the ability of staff to provide person centered care. McConnell et al (2016) and McCormack et al (2011) both note the physical environment of ED is designed with clinical demand and efficiency in mind. Concerns of infection control and requirement to utilize space flexibility during surges in demand take precedence over creation of 'person centred spaces'. For example, most ED's do not have private rooms, and subsequently patients are required to share personal and private information with only curtains to protect their privacy. Lin et al., (2013) found that when the ED was redesigned with patient privacy and dignity as forefront priorities, the patients reported increased satisfaction and increased likelihood to share a comprehensive medical and social history. Given that preservation of dignity and experience of care are two cornerstones of person centered care, it is important to consider how the physical environment may help or hinder staff in providing person centered care in ED.

However, despite the various barriers that are identified as making it challenging to provide person centred care in the ED setting, the two are not fundamentally incompatible. Person centered care refers less to 'what care is provided" and more to 'how care is provided" meaning it is theoretically possible

to embed person centered approaches in any care setting. McCormack et al (2011) outline the three key requirements for person centred care, which are 1) a positive organisational culture, 2) a learning culture, and 3) a physical environment that supports person centeredness.

Firstly, the organisational culture- defined as the shared beliefs, values, norms of behaviour, routines, traditions etc. of a defined group (Parmelli et al., 2011) plays a central role in determining environments of care. Hospitals are frequently described as having unique organisational cultures, and within the hospital it is not uncommon for ED's to develop a distinct micro-culture (Skar et al., 2015). According to McCormack et al (2011) it is the culture of a care environment- not the processes of care- that influence patients and staff most, and therefore improving care requires sustained commitment to changing organisational culture. McCormack et al (2011) suggest that to embed a person centred philosophy of care it would require establishment of "shared values" a collective redefinition of 'effectiveness', a commitment to being open to 'continual learning and improvement' and 'transformational leadership" (pg2).

Secondly, McCormack et al (2011) identify a learning culture as key to facilitation of person centered care. They define a 'learning culture' as a "*productive culture, characterized by their ability to tolerate productive tensions, learn from mistakes, support and enable innovation, maximize individual potential, and understand the interrelationship between team/system processe*s" (Pg3). This speaks directly to the challenge of breaking down the hierarchical systems in ED which are identified by McConnell et al (2016) as a major barrier to provision of person centred care in ED. McConnell et al (2016) argue that if hierarchies and power imbalances cannot be addressed between various staff groups (i.e. doctors and nurses) or staff of different seniorities (i.e. staff nurses and matrons) those power imbalances will be reflected in the care that patients receive. A core component of person- centred care is the belief that each person has equal value, even if one is in a position of needing assistance and the other a position to provide it. Therefore, embedding a learning culture that breaks down these power imbalances is an important step

in facilitating opportunities for person-centered care in ED. Lastly, McComack et al (2011) and McConnell et al (2016) highlight the importance of ensuring the physical environment supports, rather than hinders, staff provision of person centered care. In the ED context this relates to the provision of safe environments, which consider the dignity and experience of the person being treated as equal concerns with the need for clinical efficiency.

In conclusion, person centred approaches to care are not fundamentally incompatible with emergency medicine. However, there are several challenges that pose a real threat to authentic implementation of person centred approaches. There is a distinct risk that 'person centeredness' becomes a 'buzzword' or box ticking exercise that does not appreciate the complexity of commitment to organisational culture change and creation of social and physical spaces that promote person centeredness. For person centred care to be realised it will take a sustained, whole system commitment to cultivation, encouragement and sustenance of practices and cultures which facilitate person centred care (McCormack et al., 2011).

2.8 Dementia and emergency departments: an under researched area

As noted in the introduction, very little has been written and researched specifically about dementia in the ED and as such we are reliant on literature which discusses older people in ED, or dementia in acute care more generally. ED's are dynamic and complex environments where staff are required to work within a resource constrained, multi-goal system, at an extraordinary pace (Dekker, 2005). Research not grounded in this operational context is unlikely to be easily translated into the ED setting. Given the increasing number of PWD, the frequency which this patient group utilizes acute care, and the increased risks that PWD experience while they are in ED, it is essential to increase our understandings of effective approaches to care in this setting. Currently there are gaps in knowledge about;

1) The experiences of PWD and their carers while they are in the ED- and how these differ or are similar to the experiences of older people without cognitive impairments.
2) Understanding what outcomes or experiences are important to PWD when they receive care in the ED and how these differ, or are similar to, the priorities of care for adults or older adults who do not have cognitive impairments.

This research adds an original contribution to the field by investigating the ED experiences of PWD and carers. The proposed survey adds to our understanding of the drivers of satisfaction and dissatisfaction with care for this particular service user group. Additionally, themes, which emerged in the free text portion of the survey enables a preliminary discussion of the important outcomes and experiences for this group. This data alone however would be insufficient to answer the research questions of the study, and additional investigation on the staff experience of providing care for patients with complex needs in the ED setting are required. Additionally, there are current gaps in knowledge on what structural and procedural changes should be made to ensure ED services are dementia friendly. There is an emerging field of research on geriatric ED's that is explored in additional detail in the next chapter. The contribution of the qualitative portion of this research to the emerging field is explored at the end of the next chapter.

Literature review

3.1 Introduction and purpose

The purpose of this chapter is to explore and examine the existing literature on geriatric ED's and models of care that integrate geriatric approaches in ED. The decision to focus on 'geriatric emergency departments' rather than 'dementia friendly' or 'dementia in emergency departments' is due to the paucity of academic literature on programs, initiatives, and approaches to improving dementia care in ED. This limited literature on dementia in ED has been identified in literature as a major gap in knowledge by a number of academics including Clevenger et al (2012), Parke and Hunter (2016) and Schnitker et al (2013). Initial scoping searches done by the researcher and subject librarian revealed extremely limited literature on the topic, and there was a concern that reviewing this diminutive body of literature would be insufficient to demonstrate academic rigor in systematic identification and review of literature. Ergo, the decision was made to expand the systematic review to 'geriatric emergency departments' more broadly in light of this emerging field of research and practice. This enables a review of related and relevant literature that discusses health systems and institutional level change to improving ED care for patients with complex needs- such as older people with multi-morbidities or people with cognitive impairments. Additionally, review of this literature on geriatric emergency departments enables comparative analysis, critique and commentary on the similarities and differences between a 'geriatric emergency department' and a 'dementia friendly emergency department'- which is presented in chapter ten of this thesis.

The specific objectives of the literature review are to:

1) Identify what type of information is available about geriatric emergency departments.
2) Critically appraise the level of evidence and the quality of individual studies supporting this information
3) Identify key challenges in geriatric emergency medicine as defined by the literature.

4) Critically appraise the key features of geriatric emergency departments as defined by the literature, in particular;

i. Changes to the physical environment that are described, proposed, or recommended.
ii. The technical processes or care protocols that are described, proposed, or recommended.
iii. The interpersonal or interactional skills which are identified as ‘core skills’ for staff
iv. Specific staffing models that are described, proposed, or recommended.
v. The specific training and education programs that are described, proposed, or recommended.
vi. The outcomes measures described, proposed, or recommended to ensure quality and safety

This review of the literature identifies an important gap in knowledge about interpersonal and interactional skills and the impact these have on the experience of care for older people. It further identifies a need for more interventional studies to demonstrate the impact of implementing these geriatric ED principles. Additionally, this review demonstrates the primacy of ‘health systems’ outcomes as measures of success, rather than integration of patient-reported or patient-determined outcome measures.

3.2 Background

Geriatric emergency medicine is an emerging area of research and innovation. Across the world- in both developed and developing countries-older people are the fastest growing demographic population (Ellis et al., 2018). With this shift in demography there has been an increased demand on health and social care services and a growing recognition that current approaches to provision of healthcare are both financially unsustainable and failing to achieve desirable patient outcomes (*Carpenter et al., 2014; Ellis et al., 2018; Hogan, Olade, & Carpenter, 2014; Hwang & Morrison, 2016*).

In response to these challenges the Society for Academic Emergency Medicine (SAEM) and American College of Emergency Physicians (ACEP) in the United States called for a task force to evaluate the state of care for older people and to make recommendations for the future (Sanders, 1999). This task force concluded that a new approach to geriatric emergency medicine must be adopted, and a care model which recognises the specific needs of older patients should be developed *(Carpenter et al., 2014*). This task force also recommended more research is undertaken on the topic of geriatric emergency medicine, and that better education should be provided for emergency medicine staff.

The task force and call to action acted as a catalyst and research on geriatric emergency medicine has rapidly increased. For example, PubMed had 321 articles in emergency medicine specific to patients over 65 in the five years before the taskforce was created, and this increased to 4,588 in the following five years -2008-2013 (Carpenter et al., 2014). However, while this research has demonstrated the disparities in emergency care for older people, the majority of research has a single disease or single condition focus (Hwang et al., 2013). Little research has been dedicated to considering how the environment of the ED and ED care processes contribute to patient outcomes or experience (Hwang et al., 2006). Furthermore, for several years there was no clear operational definition or standards for a “geriatric emergency department”, and consequently hospitals were left to ‘self define’ leading to large disparities in service provision (Hogan et al., 2014).

In 2014, SAEM, ACEP, the American Association of Emergency Nurses, and the American Geriatric Society released “Geriatric Emergency Department Guidelines” which set out recommendations based on best practice evidence (Carpenter et al., 2014). In 2017/8 this was further developed when an accreditation process was developed which differentiates between different ‘levels of geriatric emergency departments’- tiers one, two, and three (ED Management, 2018).

While a great deal of this work has occurred in the United States, there have been concurrent developments in other places including Canada, Australia, the United Kingdom, and the EU. In Canada, a group of emergency medicine physicians has participated in the development of the US Geriatric ED guidelines, and researchers from the University of Alberta proposed a model of "Dementia friendly emergency departments" (Parke & Hunter, 2017; Parke et al., 2013). In Australia/ New Zealand the Australasian College for Emergency Medicine (ACEM) has a sub group devoted to geriatric emergency medicine. They have also released a policy on the care of elderly patients in the ED (2015) and endorse the Australia and New Zealand Society for Geriatric medicine position statement on the management of older patients in the ED (2015). In the UK, improving the quality of hospital care for older adults has been recognised as a priority for several years (Alzheimer's Society, 2009; Alzheimer's Society, 2016; Department of Health, 2015; Gladman et al., 2012; Royal College of Psychiatrists,2017; LaMantia et al., 2016) though these initiatives and calls to action have not focused specifically on care in the ED. In 2013, a multidisciplinary group of stakeholders from health, social care, and academic societies developed a "Silver Book" which is a set of standards for the emergency care of older people- including the ED (Banerjee, Conroy, & O'Leary, 2012). The National Dementia strategy from Scotland in 2010-2013 highlighted care in the ED as a priority for improvement- setting out 6 key recommendations for change (Andrews & Christie, 2009). The European Society for Emergency medicine (EUSEM) established a geriatric emergency medicine section (2015) which aims to advance knowledge in geriatric emergency medicine through organisational policy, education, and research. Finally, on an international scale, the International Federation for Emergency Medicine (IFEM) established a special interest group in geriatric emergency medicine in 2015. In 2018 IFEM released a statement on the minimum standards of care for older people in ED applicable for all countries. It is clear that geriatric emergency medicine, and geriatric ED's are becoming increasingly relevant, thus this literature review is timely and highly relevant for this project.

3.3 Methods

This is a narrative review of the literature that has utilized systematic approaches to search for and select studies, extract data, and assess quality. It was determined that a full systematic review would not be appropriate for this project as it would have been impossible to meet the standards of systematic review as establish by Cochrane for a number of reasons including 1) lack of standardised operational definition of 'geriatric emergency department" 2) limited empirical evidence gathered from primary research 3) a lack of standardised, or even similar, outcome measures. Current available literature is considerably heterogeneous and typically consists of expert opinion, review articles, and/or policy and position papers. While these types of literature can provide answers to the research questions as defined above, they do not lend themselves to systematic review methodology. However, despite this review not being a traditionally systematic one, steps have been taken to optimise search strategy and minimize risk of bias. These steps include a predefined search protocol, use of diverse search engines, predefined and clearly stated inclusion and exclusion criteria and use of a standardized tool to review quality.

PRISMA guidelines are used to guide the reporting and a flow diagram presenting the process is given in Appendix One.

3.3.1Searching

Prior to undertaking this review, 18 items were known to the researcher from previous scoping searches and hand searches. Databases that were searched for this review include CINAHL, MEDLINE and AMED. Medical subject headings and free text searches for terms related to older people, emergency medicine, and policy, guideline or recommendation were used (See Appendix two for an example of the full search strategy). As noted above, this is an emerging field of research, and as such searches were restricted to the previous 20 years. Therefore, these searches identified papers that were published in English, between January 1998 and July 2018.

3.3.2 Selection

Studies were assessed against pre-defined inclusion and exclusion criteria. The inclusion criteria included

- Published between 1998-2018
- Published in English
- Setting of the emergency department
- Referring directly to the care of older people

Exclusion criteria included

- Not published in English
- Peripheral to the emergency department i.e. pre hospital settings such as ambulance service, or post-emergency setting such as observation or short stay ward
- Exclusive focus on a single clinical issue.

Quality assessment was carried out using critical appraisal tools from the Joanna Briggs Institute at the University of Adelaide. (http://joannabriggs.org/research/critical-appraisal-tools.html) This quality appraisal approach was selected as there is considerable variation in the type and sources of literature, and the Joanna Briggs Institute offers a standardised appraisal checklist that has multiple versions, which have been modified for different types of data. Additionally, each item was scored using Polit and Beck's (2008) hierarchy of evidence.

Figure 9: Polit and Beck (2008) Hierarchy of Evidence

Level 1:	Systematic reviews of randomized and non-randomized clinical trials
Level 2	Single randomized and non-randomized clinical trials
Level 3:	Systematic review of correlational and observational studies
Level 4	Single correlational and observational studies
Level 5:	Systematic review of descriptive, qualitative, and physiologic studies
Level 6:	Single descriptive, qualitative, and physiologic studies
Level 7:	Opinions from authorities, and expert committees

For a summary of the included literature including hierarchy scoring, please see Appendix Three.

Initial searches identified 1508 items, which resulted in 1075 unique records when duplicates were automatically removed using reference management software. The remaining 1075 titles were screened for preliminary assessment of relevance. This first round of screening excluded articles if they were not specifically about older people (- 609) or not specifically about the ED (-317). An additional 56 duplicates which had been overlooked by the reference management software were manually identified as a result of the title screening and were subsequently removed. Two articles not in English were also removed at this stage, leaving a total of 91 items to be further reviewed.

The second round of assessment was based on information provided in the article abstract. For this round, exclusion criteria included the article not being specifically about older adults (12) or not specifically set in the ED (7) for example, articles about ambulance transfer and observation units. Additionally, articles that focused exclusively on one clinical issue in the ED (falls, myocardial infarction, delirium screening etc) were excluded (36). While this literature offers valuable perspective on opportunities to improve care, this particular body of literature does not directly contribute to addressing the review objectives defined above, i.e. identification of health systems or institutional level features of geriatric ED's.

For a full overview of the 38 included items of literature- including description of methods and potential limitations- please see appendix three. Eight items are correspondence to the editor, opinion pieces, or announcements in newsletters (American Geriatrics Society, 2017; Dent et al., 2016; ED Management, 2018; Miller, 2012; Nursing Older People, 2011; Saliba, 2018; Sanders, 1999; Wolfe, 2006) The announcements (ED Management, 2014; Nursing Older People, 2011; Saliba, 2018) do not offer substantive content, and as such do not contribute to the overall body of evidence examined here. The opinion pieces and correspondence to editors are included despite being assessed as "low quality" after appraisal and mindful of the

convention that expert opinion is considered low in the hierarchy of evidence. A study protocol (Martin-Khan et al., 2013) published in a journal in 2013 is also included as it meets the pre-defined inclusion/exclusion criteria. However, it has been assessed as being low quality evidence, and due to the format does not make a substantive contribution to this review.

The search identified two literature reviews (Clevenger et al., 2012; Schnitker et al,. 2013) and two other reviews of older peoples' experience in emergency departments were previously known to the researcher and added to this review (Aminzadeh & Dalziel, 2002; Salvi et al., 2007). Also included are two descriptive papers on knowledge, skills and training (Kennelly et al., 2013; Rawson et al., 2017) and two studies which discuss the development of a geriatric emergency medicine curriculum (Conroy et al., 2016; Hogan et al., 2010). Additionally, there are two interventional studies (Aldeen et al., 2014; Shanley et al., 2009). Three national level strategies or guidelines were identified in the search (USA, Canada, UK) and an additional three (Australia, New Zealand, and EU) were previously known to the researcher and subsequently added. Additionally, the statement position by the International Federation of Emergency Medicine on minimum standards is included (Ellis et al., 2018). Lastly, 13 papers describing the characteristics of an "age friendly", "dementia friendly" or "geriatric" ED's were identified by the search and are included (Burton, Young, & Bernier, 2014; Carpenter et al., 2014; Devriendt et al., 2017; Hogan et al., 2014; Hwang et al., 2013; Hwang & Morrison, 2016; Joanna Briggs Institute, 2012; Kennelly et al., 2013; McClelland & Sorrell, 2015; Melady & Perry, 2018; Parke & Hunter, 2017; Perry, Tejada, & Melady, 2018; Ryan, Splinter Flynn, & Wilding, 2017). These are typically descriptive papers, written by experts in the field that present arguments for the need to develop geriatric ED's with reference to existing literature. These papers do not report on original research, and there is considerable heterogeneity in the findings and conclusions. Of particular note is the limited number of authors who contribute to this overall body of literature. Many authors (I.e. Banerjee, Carpenter, Conroy, Hwang, Melady, Parke, ect) appear as authors or co-authors for

multiple papers. This is indicative of the limited number of researchers and practitioners currently engaged with this area of research. While the multiple publications in peer reviewed journals- and the credentials of the authors- suggests these authors can be considered subject matter experts, the potential impact of a small number of perspectives must be considered.

Thus, a total of 38 papers are included in this review, though only 34 make a substantive contribute to the analysis. The largest number of studies came from the USA (15) followed by Australia/New Zealand (8) Canada (6) and the UK (4). Two papers report on international collaborations, and Italy, Ireland, and Belgium are represented by one study each.

3.4 Results

3.4.1 Key challenges in geriatric emergency medicine

The most frequently referenced challenge in geriatric emergency medicine is the increasing volume of geriatric patients who attend ED (Aldeen et al., 2014; American College of Emergency Physicians et al., 2013; Andrews & Christie, 2009; Banerjee et al., 2012; Carpenter et al., 2014; Hwang et al., 2013; Joanna Briggs Institute, 2012; McClelland & Sorrell, 2015; Perry et al., 2018; Ryan et al., 2017; Salvi et al., 2007; Shanley et al., 2009). Across all of the countries represented in these papers, the proportion of older people is projected to rise rapidly, and this is reflected in the patterns of use of emergency services. Several studies reported that older people are consistently over represented in ED attendee statistics compared with their proportion within the general population in the geographic area (Aminzadeh & Dalziel, 2002; Banerjee et al., 2012; Carpenter et al., 2014; Hwang & Morrison, 2016). Concurrent to this there is a growing recognition that the current model of service delivery is unsustainable and not achieving desirable health or social outcomes (American College of Emergency Physicians et al, 2014; Aminzadeh & Dalziel, 2002; Hwang et al., 2013; Martin-Khan et al., 2013; McClelland & Sorrell, 2015; Salvi et al., 2007). Aminzadeh and Dalziel (2002) summarize the challenge succinctly, noting that "*the current disease-oriented and episodic*

models of emergency care do not adequately respond to the complex care needs of frail older patients"(p238) and this leads to a risk that emergency care systems may be over- whelmed unless they are redesigned to address the care needs of older adults (Hwang et al., 2013; McClelland & Sorrell, 2015).

One reason the current, single complaint, episodic model of care does not work well for older patients is the complexity of their health and social care needs (Aldeen et al., 2014; Aminzadeh & Dalziel, 2002; Australian and New Zealand Society for Geriatric Medicine, 2015; Banerjee et al., 2012; Clevenger et al., 2012; Devriendt et al., 2017; Hwang et al., 2013; Joanna Briggs Institute, 2012; McClelland & Sorrell, 2015; Melady & Perry, 2018; Parke & Hunter, 2017; Perry et al., 2018; Ryan et al., 2017; Shanley et al., 2009). Older people are more likely to present with multiple co-morbid conditions including cognitive impairment, functional impairment, poly-pharmacy, and have their discharges complicated by social concerns. Another dimension to this complexity is the frequency with which older patients experience atypical presentation of disease (Aldeen et al., 2014; Banerjee et al., 2012; Burton et al., 2014; McClelland & Sorrell, 2015; Melady & Perry, 2018; Shanley et al., 2009). This atypical presentation can lead to a variety of harms including under-triage (Australian and New Zealand Society for Geriatric Medicine, 2015; Hwang et al., 2013; McClelland & Sorrell, 2015; Melady & Perry, 2018; Perry et al., 2018*)* and inaccurate diagnosis. Subsequently, as a result of the incompatibility of the complexity of the patients and the current emergency care model, older people are more likely to experience an adverse outcome either during, or after a visit to ED; including development of delirium, medication errors, falls, decline in functional status, cognitive loss, and nursing home admission (Aldeen et al., 2014; Andrews & Christie, 2009; Australasian College for Emergency Medicine, 2015; Banerjee et al., 2012; Burton et al., 2014; Clevenger et al., 2012; Hwang et al., 2013; Joanna Briggs Institute, 2012; McClelland & Sorrell, 2015; Perry et al., 2018; Salvi et al., 2007; Shanley et al., 2009). Additionally, older people are more likely to be admitted to the hospital(Aldeen et al., 2014; American College

of Emergency Physicians et al., 2013; Aminzadeh & Dalziel, 2002; Andrews & Christie, 2009; Salvi et al., 2007).

Another possible explanation for the poor experiences of care that older people frequently report in ED (American College of Emergency Physicians et al., 2013; Hwang et al., 2013; Martin-Khan et al., 2013; Salvi et al., 2007) is the physical environment which is unsuitable for older people and the lack of geriatric specific resources (Aldeen et al., 2014; American College of Emergency Physicians et al., 2013; Andrews & Christie, 2009; Burton et al., 2014; Joanna Briggs Institute, 2012; McClelland & Sorrell, 2015). The importance of the physical environment is explored in additional detail below. It is also known that older people require more resources while they are in ED; including additional imagining and laboratory tests, as well as more staff time (Aldeen et al., 2014; American College of Emergency Physicians et al., 2013; Andrews & Christie, 2009; Burton et al., 2014; Joanna Briggs Institute, 2012; McClelland & Sorrell, 2015; Melady & Perry, 2018). If these resources are not available in ED or care is constrained by efficiency targets, the patient may be admitted to the hospital unnecessarily (Aldeen et al., 2014; Australian and New Zealand Society for Geriatric Medicine, 2015; Hwang et al., 2013; McClelland & Sorrell, 2015).

The social environment of the ED is equally important in determining the older person's experience of care. In particular, the current model of care can fail to identify older peoples' complex psychosocial needs, or, if identified, fail to be address them appropriately (McClelland & Sorrell, 2015; Melady & Perry, 2018). This is compounded by beaurocratic pressures to achieve efficency (Melady & Perry, 2018; Parke & Hunter, 2017), a lack of best practice guidance for geriatric patients with complex needs in ED (American College of Emergency Physicians et al., 2013; Clevenger et al., 2012; McClelland & Sorrell, 2015; Parke & Hunter, 2017), and lack of effective, context specific, training opportunities in geriatric emergency medicine (American College of Emergency Physicians et al., 2013; Carpenter et al., 2014; Conroy et al., 2016; Devriendt et al., 2017; Hogan et al., 2010; Ryan et al., 2017)

Lastly, there are factors outside the ED that are affecting the quality and safety of care that is provided for older patients. A key challenge is the strained infrastructure of primary care, which is leading to older patients arriving in ED more acutely ill, and seeking treatment for worsening of chronic conditions which would more appropriately be treated by a primary care provider (Ellis et al., 2018; Hogan et al., 2014; Hwang et al., 2013). Parallel to this increased strain on the primary care infrastructure and aging population, there are a declining number of geriatricians proportional to the increase number of patients who may traditionally benefit from geriatric specific medical consultation. This can lead to challenges for ED staff if they attempt to seek expert advice and there is no geriatrician input available within the hospital (Carpenter et al., 2014; Hogan et al., 2014; Ryan et al., 2017).

3.4.2 Physical Environment

The content on physical environment in the literature ranges from passing reference to the impact of environmental concerns in the in the background section of the opinion pieces and quasi-experimental studies, to comprehensive recommendations on lighting, acoustics, equipment, and departmental layout in the guidelines. There is widespread acknowledgement that the typical environment of ED is too loud, too busy, and too bright for older people, which is recognised as overstimulation, distressing and risks increasing confusion (American College of Emergency Physicians et al., 2013; Andrews & Christie, 2009; Banerjee et al., 2012; Burton et al., 2014; Carpenter et al., 2014; Dent et al., 2016; Hogan et al., 2014; Hwang et al., 2013; Joanna Briggs Institute, 2012). Therefore, it is recommended that changes are made to the physical environment of the ED with a particular focus on implementing changes which promote independence, improve safety and mobility, provide memory cues, and reduce overstimulation due to sensory overload (American College of Emergency Physicians et al., 2013; Australasian College for Emergency Medicine, 2015; Australian and New Zealand Society for Geriatric Medicine, 2015; Banerjee et al., 2012; Hwang et al., 2013; Melady & Perry,

2018). The importance of physical environment is reflected in the two studies which review common features of geriatric ED services (Hogan et al., 2014; Ryan et al., 2017). Hogan et al (2014) found that 90% of sites identified as 'a geriatric ED' self reported they had made changes to the physical environment to improve care, and Ryan, Splinter Flynn and Wilding (2017) report that 96% of their sites reported changes in the physical environment in the survey they used to gather data.

An entirely separate area for assessment and treatment of older people is considered as 'Gold standard' (American College of Emergency Physicians et al., 2013; Banerjee et al., 2012; Joanna Briggs Institute, 2012). However, it is recognised that it is not always feasible to create a distinct area specifically for older people- and in that instance, the recommendations suggest at minimum there should be a visually distinct area that embodies the design principles and equipment provision as recommended for the 'gold standard' separate area (American College of Emergency Physicians et al., 2013; Andrews & Christie, 2009; Australasian College for Emergency Medicine, 2015; Australian and New Zealand Society for Geriatric Medicine, 2015; Melady & Perry, 2018). Parke and Hunter (2017) offer a voice of dissent from the others on this issue suggesting that a distinct area would inevitably fail to have capacity to provide care for the entire geriatric population and therefore there would be a rationing of 'best practice care' which would be unethical. As an alternative, they propose that the entirety of any ED should have physical and social adaptations to provide person centered, older person appropriate care. This championing of 'person centered environments' is also found in the position statements from The Australian and New Zealand Society of Geriatric Medicine (2015), and is referenced by Melady and Perry (2018) and Banerjee et al (2012). Overall, there is widespread acknowledgment of the importance of ensuring the physical environment is appropriate to the needs of older patients, but the level of detail and prescriptiveness of recommendations provided in the literature varies widely.

3.4.3 Technical processes

The majority of evidence sources itemize the need for some form of geriatric specific technical process in the form of protocols or standardised assessments. Unsurprisingly, the most detailed and prescriptive guidance on recommended protocols comes from two published guidelines (American College of Emergency Physicians et al., 2013; Banerjee et al., 2012). The other sources provided a range of guidance- from generalised statements on the value of cognitive, functional and social assessment, to detailed descriptions of best practice tools for assessment that should be used. The purpose of embedding these standardized assessments and protocols in routine ED care is to bring more evidence based practice to geriatric ED care and improve the likelihood that the older patient has a comprehensive and holistic assessment (American College of Emergency Physicians et al., 2013; Aminzadeh & Dalziel, 2002; Conroy et al., 2016; Hwang et al., 2013; McClelland & Sorrell, 2015; Melady & Perry, 2018; Ryan et al., 2017; Salvi et al., 2007). The protocols that are recommended in the literature can be separated into three general categories; cognitive, functional or medical, and social.

The importance of screening for cognitive function is recognised in nearly every included source which discussed technical protocols for geriatric ED's (Aldeen et al., 2014; American College of Emergency Physicians et al., 2013; Andrews & Christie, 2009; Banerjee et al., 2012; Carpenter et al., 2014; Hwang et al., 2013; Melady & Perry, 2018; Parke & Hunter, 2017; Perry et al., 2018; Ryan et al., 2017; Schnitker et al., 2013; Shanley et al., 2009). Cognitive screening is most frequently used to describe assessment for dementia and delirium in ED, but in some cases included depression screening as well. A variety of tools to assess cognitive function are proposed including the confusion assessment method, Mini-Cog, Mini Mental State Examination, Montreal Cognitive Assessment, and Dementia Quick Screen. The Geriatric ED guidelines specify, "*validated assessment tools should be used to identify patients presenting with dementia or delirium*" and recommend the delirium triage screen and brief confusion assessment method as proposed best

practice. However, any assessment tool that has been validated for use in ED can fulfil this recommendation provided it is consistently applied. Self reported evidence gathered from geriatric ED's in the US suggests that cognitive screening is carried out in 87% of sites and (Hogan et al., 2014) and 70% of Ontario ED's with geriatric nurses embedded in ED reported cognitive screening when responding to targeted requests for feedback from researchers (Ryan et al., 2017). While these high percentages suggest considerable consistency of cognitive screening in geriatric ED's, it is important to be mindful of the potential limitations of self-report when determining the robustness of this evidence.

Similarly, functional or medical assessment is identified as a core feature of geriatric ED service provision (Aldeen et al., 2014; American College of Emergency Physicians et al., 2013; Andrews & Christie, 2009; Australasian College for Emergency Medicine, 2015; Australian and New Zealand Society for Geriatric Medicine, 2015; Banerjee et al., 2012; Burton et al., 2014; Carpenter et al., 2014; Dent et al., 2016; Devriendt et al., 2017; Hogan et al., 2014; Hwang et al., 2013; Joanna Briggs Institute, 2012; McClelland & Sorrell, 2015; Melady & Perry, 2018; Parke & McCusker, 2008; Parke & Hunter, 2017; Perry et al., 2018; Ryan et al., 2017; Schnitker et al., 2013; Shanley et al., 2009). A variety of functional and medical assessments are proposed including falls, mobility and gait, medications review, continence, skin integrity, activities of daily living, independent activities of daily living, atypical presentation, and pain assessments. Additionally, protocols to reduce use of indwelling urinary catheters, ensure safe sedation, and reduce potentially inappropriate medications are recommended. The implementation of geriatric focused technical process- such as standardized assessment or use of protocols- was the most commonly reported adaptation proposed or recommended in the literature. Ryan (2017) indicates that 96% of geriatric ED nurses in Ontario self report carrying out functional assessments as part of their job and Hogan et al (2014) found 87% of geriatric ED's in the US self-report functional assessment as a component of their geriatric ED program. Embedding these geriatric focused assessments and protocols is a key component in improving the

standardisation, quality, and safety of care for older people in emergency medicine.

Lastly, a number of studies proposed that alongside the cognitive and functional or medical assessment, a range of assessments addressing social concerns should be carried out in the ED (American College of Emergency Physicians et al., 2013; Banerjee et al., 2012; Hwang et al., 2013; Melady & Perry, 2018; Perry et al., 2018; Ryan et al., 2017; Shanley et al., 2009). These social assessments included review of caregiver burden or burnout, living situation, risk of imminent transition in care location, identification of individuals who are high risk, and protocols for identifying abuse of older people. These social assessments are designed to identify and address some of the non-biomedical concerns that sometimes bring older people to the ED. These assessments were more frequently proposed in nurse-led or multidisciplinary assessment models- as opposed to physician-led assessment models- which could be explained in part by constraints on physician time, the medico-technical focus of ED medicine and the perceived time investment required for comprehensive social assessments reported by McConnell et al (2016).

Overall, the literature supports the conclusion that there is a sufficient body of evidence to develop and implement evidence based guidelines for best practice care of older people in emergency departments (Carpenter et al., 2014). However, despite this evidence, there is still a lack of consensus on which tools are most effective and appropriate and a wide variation of approach to, and extent of, implementation are reported.

3.4.4 Interpersonal processes

Interpersonal processes are defined by Donabedian as “the manner in which care is delivered” which is distinct from technical process which relate more to the type of care that is delivered (Donabedian, 2003). In this context, interpersonal processes are reflected by the approach and philosophy of care that underpins care delivery. When compared to technical processes, considerably fewer papers made explicit reference to the approach or

philosophy of care that should guide care delivery at the bedside. Explicit reference is made in Andrews and Christie (2009), the Australasian College for Emergency Medicine (2015) the Australian and New Zealand Society for Geriatric Medicine (2015), Banerjee, Conroy & O'Leary (2012), Hwang et al (2013), the Joanna Briggs Institute (2012), McClellend and Sorrell (2015), Parke and Hunter (2017) and Melady and Perry (2018). For this review, papers were assessed as making a contribution to 'interpersonal processes' if they made one or more explicit references to shared decision making (Andrews & Christie, 2009; Australian and New Zealand Society for Geriatric Medicine, 2015; Banerjee et al., 2012; Hwang et al., 2013; Joanna Briggs Institute, 2012; Melady & Perry, 2018; Parke & Hunter, 2017), management of distressed or agitated behaviours with person centered approaches (Andrews & Christie, 2009; Australian and New Zealand Society for Geriatric Medicine, 2015; Hwang et al., 2013; Joanna Briggs Institute, 2012) or provided discussion of the importance of creating a social climate that prioritises holistic care (Australian and New Zealand Society for Geriatric Medicine, 2015; Joanna Briggs Institute, 2012; McClelland & Sorrell, 2015; Parke & Hunter, 2017).

Several other papers discuss the value of employing nurses trained in geriatric nursing principles in ED (Aldeen et al., 2014; American College of Emergency Physicians et al., 2013; Burton et al., 2014; Hogan et al., 2014; Melady & Perry, 2018; Perry et al., 2018; Ryan et al., 2017). Geriatric nursing principles- as defined by Melady and Perry (2018)- are grounded in relationship centered, or person centered care, and could be considered as 'making reference' to the importance of interpersonal processes. In the literature, however, these connections were not explicitly made. Interpersonal processes are considerably harder to quantify, and therefore it is important to be mindful that the absence of explicit mention of approach or philosophy of care should not be taken as an indication that these principles are not prioritized by the authors or embedded into the proposed models of care.

3.4.5 Staffing models

There is a wide range of guidance provided in the literature ranging from passing reference to the importance of multi-disciplinary approaches in opinion and descriptive articles, to descriptions of existing team structures, and fully developed staffing recommendations in the quasi experimental studies and guidelines. The most common recommendation about staffing a geriatric ED is that a multidisciplinary approach is key to success (Aldeen et al., 2014; American College of Emergency Physicians et al., 2013; Andrews & Christie, 2009; Australasian College for Emergency Medicine, 2015; Australian and New Zealand Society for Geriatric Medicine, 2015; Banerjee et al., 2012; Burton et al., 2014; Carpenter et al., 2014; Devriendt et al., 2017; Ellis et al., 2018; Hogan et al., 2010, 2014; Joanna Briggs Institute, 2012; McClelland & Sorrell, 2015; Melady & Perry, 2018; Miller, 2012; Parke & McCusker, 2008; Parke & Hunter, 2017; Perry et al., 2018; Ryan et al., 2017; Salvi et al., 2007; Schnitker et al., 2013; Shanley et al., 2009; Wolfe, 2006). Within this literature, five articles discuss the structures of existing teams (Aldeen et al., 2014; Devriendt et al., 2017; Hogan et al., 2014; Ryan et al., 2017; Shanley et al., 2009) six offer explicit recommendations on staffing models (American College of Emergency Physicians et al., 2013; Banerjee et al., 2012; Carpenter et al., 2014; Hwang et al., 2013; Melady & Perry, 2018; Perry et al., 2018), and the remaining articles discuss or make reference to the importance of ensuring the staffing approach is multi-disciplinary.

Within the literature a variety of models are proposed. This can be broadly broken into nursing-led models, physician-focused models, and blended models. The nursing-led models described by Aldeen et al (2014), the Joanna Briggs institute (2012) Ryan et al (2017), Shanley et al (2009) and Wolfe (2006) focus either on up-skilling ED nursing in geriatric assessment, or embedding geriatric trained nurses into the existing ED structures. The aim of these programs is typically to improve holistic assessment and facilitate a more effective patient pathway either into the hospital or back into the community with appropriate support. In contrast, the models which focus more on the

physician's role in assessment (American College of Emergency Physicians et al., 2013; Carpenter et al., 2014; Conroy et al., 2016; Devriendt et al., 2017; Hogan et al., 2010; Melady & Perry, 2018) tend to concentrate on improving medical assessment of older people. It should be noted however, that these physician focused models still champion the need for multidisciplinary teams, and note that nursing staff have an essential role in provision of holistic care in the ED setting. The suggested makeup of the multidisciplinary teams varies, but typically includes at least four of the following; pharmacist, physical therapy, occupational therapy, social worker, geriatrician, discharge co-ordinator, and/or elder life specialists. The Geriatric ED guidelines provided by the American College of Emergency Physicians are the most prescriptive, setting out the requirement for physician, nursing, and allied health professional staffing explicitly (American College of Emergency Physicians et al., 2013) whereas the other recommendations are less prescriptive.

3.4.6 Training

The importance of having specialty trained staff in ED, or providing access to previously established geriatric training programs for ED staff was referenced by a majority of articles included in this review (Aldeen et al., 2014; American College of Emergency Physicians et al., 2013; Aminzadeh & Dalziel, 2002; Andrews & Christie, 2009; Australasian College for Emergency Medicine, 2015; Banerjee et al., 2012; Burton et al., 2014; Carpenter et al., 2014; Clevenger et al., 2012; Conroy et al., 2016; Devriendt et al., 2017; Ellis et al., 2018; Hogan et al., 2010, 2014; McClelland & Sorrell, 2015; Melady & Perry, 2018; Miller, 2012; Parke & McCusker, 2008; Parke & Hunter, 2017; Perry et al., 2018; Ryan et al., 2017; Salvi et al., 2007; Shanley et al., 2009; Wolfe, 2006). Within this body of literature, three papers describe the process of developing standards or guidelines for training programs (Conroy et al., 2016; Hogan et al., 2010; Parke & McCusker, 2008) and five describe the training embedded in programs already running (Aldeen et al., 2014; Hogan et al., 2014; Ryan et al., 2017; Shanley et al., 2009; Wolfe, 2006). The remaining

articles describe either a need for more, or better, training in geriatric specific concerns for ED staff, or a need for geriatric trained staff to be available in the ED (American College of Emergency Physicians et al., 2013; Aminzadeh & Dalziel, 2002; Andrews & Christie, 2009; Australasian College for Emergency Medicine, 2015; Banerjee et al., 2012; Burton et al., 2014; Carpenter et al., 2014; Clevenger et al., 2012; Ellis et al., 2018; Hwang et al., 2013; McClelland & Sorrell, 2015; Melady & Perry, 2018; Parke & Hunter, 2017; Perry et al., 2018; Salvi et al., 2007).

The purpose of improved or enhanced training is two fold- firstly to increase the skill of healthcare staff undertaking geriatric assessment, and secondly to change attitudes and increase understanding. Both Hogan (2014) and Conroy et al (2016) describe the process of developing a post registration curriculum for physicians based on a core competencies model. This approach is reflected in the American College of Emergency Physicians guidelines (2014), the UK guidance on quality care for older people (Banerjee et al., 2012) and also found in the Australian College of Emergency Medicine position statement (2015). Burton et al (2014) recommends that geriatric EDs should be staffed by physicians who have had fellowship training in geriatric emergency medicine, but notes that opportunities for geriatric ED fellowships in the USA are limited. The core competencies which are highlighted in these papers include; atypical presentations of disease, trauma including falls and hip fracture, cognitive and behavioural disorders, modifications for older patients of emergency interventions, medication management, transitions of care and referrals to services, pain management and palliative care, effect of comorbid conditions, functional impairments and disorders, management of diseases peculiar to the geriatric adult (including conditions causing abdominal pain, weakness and dizziness, iatrogenic injuries), cross-cultural issues involving older patients in the emergency setting, elder abuse and neglect, and ethical issues including advance directives (American College of Emergency Physicians et al., 2013; Banerjee et al., 2012; Conroy et al., 2016; Hogan et al., 2010; Melady & Perry, 2018). For nursing education, completion of the Geriatric

Emergency Nursing Education (GENE) online course or the Geriatric Education for EMS (GEMS) course are recommended (Aldeen et al., 2014; American College of Emergency Physicians et al., 2013; Hogan et al., 2010; Melady & Perry, 2018; Ryan et al., 2017; Shanley et al., 2009*)* and Melady and Perry (2018) also reference the online GERI-ED and GERI-EM websites as sources of continuing professional development.

Interestingly, Andrews and Christie (2009), Clevenger et al (2012) and Parke and Hunter (2017) all place additional emphasis on the importance of training which targets changes in attitudes, increases in understanding and focuses on hands on skills. These three papers focus specifically on the experiences of people with dementia in ED. This suggests that research which focuses specifically on PWD, and the experiences of PWD in ED, have identified opportunities for improvement through changing perspectives, attitudes, and increasing understanding of dementia. Additionally, it suggests that those with experience working in a 'front line care role' for PWD- such as Andrews, Parke and Hunter who are all registered nurses with a special interest in dementia in addition to their academic roles- recognise the importance of hands on, skills based training to improving care for patients. Therefore, the approach to training, and the skills that are prioritized in institutional policy-technical versus interactional-may be indicative of a key difference between 'geriatric friendly emergency rooms' and 'dementia friendly emergency rooms'.

3.4.7 Outcomes

A number of outcome measures are described, proposed or recommended in the literature. The outcome rationale is to demonstrate that implementing geriatric ED practices can improve health systems functioning and enhance patient experience and outcomes. However, it is important to note that as of 2014, no geriatric ED could demonstrate measureable differences in health system or patient outcomes as a result of the geriatric adaptations (Hogan et al., 2014). Hogan et al attributes this in part to inconsistent standards of implementation and in part to failure to identify

appropriate outcome measures to accurately measure impact. For example, 70% of geriatric ED's measure patient satisfaction, but there is insufficient differentiation of the drivers of satisfaction/dissatisfaction to identify if the changes that have been made improve patient experience.

Outcomes which are proposed to measure impact of implementing geriatric ED principles on health systems function include admissions avoidance (Aldeen et al., 2014; American College of Emergency Physicians et al., 2013; Andrews & Christie, 2009; Ryan et al., 2017), reduced length of stay (Aldeen et al., 2014; Hogan et al., 2014; Ryan et al., 2017) reduced costs (Aldeen et al., 2014; American College of Emergency Physicians et al., 2013) more appropriate allocation of resources, and follow up with patients after discharge to prevent re-presentation (American College of Emergency Physicians et al., 2013). Additionally, it has been suggested that better identification of geriatric syndromes and atypical presentation in ED can reduce risk of iatrogenic harm (Melady and Perry 2018; Banerjee, Conroy, and O'Leary, 2012) though this is somewhat tempered by the recognition that identification of geriatric syndromes in ED does not necessarily correlate with provision of best practice care in the inpatient setting. Aldeen et al (2014) found that after implementing a comprehensive geriatric nursing assessment in the ED the length of stay in the ED for patients seen by the nurses increased, but the likelihood of admission to hospital decreased. Overall, there is a clear need for a large scale evaluation of geriatric ED's once the accreditation and standardisation programs proposed by ACEP have been implemented to determine what impact these guidelines have on measurable outcomes. Due to the complexities of geriatric medicine and the needs driven operational environment of ED's, a realistic evaluation which can assess implementation fidelity and offer a critical appraisal of potential barriers and facilitators may be more effective in demonstrating impact than a traditional 'outcomes' focused research.

In addition to health systems outcomes, several studies note the potential benefits for patients including more comprehensive assessment (American College of Emergency Physicians et al., 2013; Banerjee et al., 2013;

Ellis et al., 2018; Hwang et al., 2013), better experience of care (American College of Emergency Physicians et al., 2013; Andrews & Christie, 2009; Banerjee et al., 2012; Ellis et al., 2018; Hwang et al., 2013; Parke & Hunter, 2017) and reduced stress and anxiety for the patient while in the department (Andrews & Christie, 2009; Joanna Briggs Institute, 2012; Parke & Hunter, 2017). It is clear that health systems indicators are proposed or recommended as outcome measures more frequently than patient outcomes. This could potentially be explained by the need to demonstrate cost effectiveness, but represents an important gap in the current program of geriatric emergency medicine research. No papers made explicit reference to patient-defined, patient-identified, or patient reported outcomes (beyond satisfaction) as point of measurement to assess success of the program. The use of patient defined and reported outcome measures is rapidly increasing in quality improvement research and the approach has been championed by the NHS as a means of measuring and improving clinical quality (Clancy & Eisenberg, 1998; Dawson et al, 2010). Therefore, the absence of these patient reported outcomes is a notable omittance.

3.5 Discussion

It is clear that the single complaint, episodic model of emergency medical care is not equipped to provide high quality, comprehensive, person centered care for older people with complex needs. A new care model that more appropriately addresses the various medical and social complexities of the needs of older people could improve the safety and experience of care for older people. Important work has been done to date which defines best practice standards for the physical environment, establishing what policies and protocols are required to provide best practice care, defining effective staffing models, and outlining the staff training needs for a geriatric ED model. The future work of tiered accreditation for Geriatric ED's planned by the American College of Emergency physicians, referenced in the media release from ED Management, will hopefully act as a catalyst to bring increased standardisation. However, this

is clearly an emerging field and there is additional work required to further underpin implementation and establish standardization.

A particular critique of the geriatric ED literature is that it is excessively focused on improving the technically processes of medical care for older people. This could be considered to be misaligned with the priorities of care of older people- as identified in the background chapter- that typically are related to the importance of a relationship with the care provider. This is not to suggest that practitioners who work in geriatric ED's do not prioritize or facilitate the provision of relationship-centered care. In fact, these interpersonal and relational skills are deeply embedded in the ethos of geriatric and palliative care medicine and any staff who undertake specialist 'geriatric ED training" would be exposed to these approaches to care. However, these 'soft skills' are not highlighted or made explicit within the majority of the literature, suggesting a continued primacy of the medical model. Further research on patient defined outcomes of 'good care', and a commitment to enshrining these patient defined outcomes would strengthen the representativeness of this work gong forward.

The growing movement towards embedding geriatric ED principles into emergency care, despite a lack of empirical evidence demonstrating efficacy or cost effectiveness is particularly notable. It suggests a recognition by front-line staff that the current model is serving no one's best interests, and the perceived benefits for the health system (i.e. cost savings, better patient flow, better patient safety), the patient (i.e. better outcomes and better experiences of care) and for staff (reducing stress and anxiety associated with management of complex older patients) are sufficient to justify provisional implementation. However, implementation to date has largely been sporadic and adaptations have happened incrementally. This piecemeal implementation is a potential explanation for the failure to demonstrate effectiveness of the geriatric ED principles, as small alterations are unlikely to create meaningful change within a large, complex system. A full systems approach is required to create impact, and implementing this full systems change will require at least some up front funding. Strong, empirical evidence of cost effectiveness and demonstrated

impact will inevitably be required to convince funders long-term investment is worthwhile.

3.5.1 Limitations

There are some limitations to this review that should be noted. Firstly, for pragmatic reasons, the search was limited to articles published in English only. This excludes literature describing geriatric ED innovations outside of English speaking nations. Secondly, it is important to bear in mind that a large majority of the evidence sources included fall low on the hierarchy of evidence- with a large number consisting of background information or opinion pieces. While this is likely a result of the emergent nature of this research, it is important to bear in mind. Lastly, the majority of these articles do not speak directly to the experiences of people living with dementia, as their focus is on older people more broadly. In addition to the challenges that many older people experience with mobility or sensory impairment, PWD can also have their experience of care in ED affected by confusion, disorientation of time and space, word finding problems, memory challenges, and experiences of discrimination or stigma as a result of their dementia. Therefore, careful consideration of the unique needs and experiences of PWD is required to determine which of these suggestions are applicable and appropriate to PWD.

3.5.2 Original contribution

The research in this thesis provides an original contribution to the field by specifically exploring the experiences of PWD in ED. Additionally, the use of co-design to develop the research tools is an entirely novel approach in this specific aspect of inquiry as co-design approaches are not reported in existing literature. This enables a critical appraisal of what structural, procedural and educational recommendations are appropriate to the context of ‘dementia friendly emergency departments’ as opposed to “geriatric emergency departments”.

Furthermore, this research utilizes a mixed methods approach to gather the perspectives of patients and carers, while also exploring the barriers and

facilitators of good care as identified by staff. This approach is unique in the literature, as earlier research has tended to focus on one group or the other which inevitably fails to capture the complexity of the relationships and interactions between patient, provider and health system. In particular, the literature clearly defines what “good geriatric emergency care” is from a technical, and at times social, perspective, but fails to offer explanation as to why these practices are not being utilized more frequently. By exploring the barriers and facilitators to good care, we can determine where to prioritize interventions to remove barriers and support facilitators of good dementia care. The importance of identifying and removing these barriers is particularly relevant in the context of supporting and enabling staff to deliver person centered care, which will be explored in detail in chapters eight and nine.

Methodology

4.1 Introduction and purpose

This chapter discusses the overarching philosophies and approaches that guided the research. Section two contains a discussion of the ontology and epistemology and justifies the decision to adopt a pragmatic ontology. It further discusses how dementia can be conceptualised from both realist and constructionist perspectives, but ultimately concludes that methodological purism is inappropriate for this research and therefore relies upon critical realism as an epistemological stance. The relationship between the pragmatic ontology, critical realist epistemology, and use of mixed methods as an investigative method is then explored.

Section three focuses on the theories and approaches to patient safety and quality improvement that informed this research. An introduction outlines the idea of 'safety' in healthcare, and then tracks the evolution of patient safety. This is followed by an introduction to the amalgam of disciplines collectively known as human factors in patient safety and quality improvement. The section then offers a rationale for using the human factors approach in this project by exploring the difference between 'complex' and 'complicated', demonstrating that a human factors approach is most appropriate to address the complex challenges inherent in the provision of emergency medicine. The section concludes with a discussion of asset- based problem solving and positive deviance- and how these approaches can be used to support human factors research.

The final section of this chapter discusses the importance, which was given to facilitating the participation of PWD in this research. Including PWD as active research partners was a core value of the research approach from the outset, which had a significant impact of the choice of methods. This section will discuss how this research was directed by the dual priorities of enabling people participation and ensuring the research was conducted ethically.

4.2 Ontology and Epistemology

Ontology is a branch of metaphysics, which focuses on questioning the nature of reality and what is argued to exist. Traditionally, research philosophies have been divided into a two-paradigm approach with some such as Smith (1984, 1985, 1989) arguing that the positions of realism and constructionism are fundamentally different from one another at an ontological level and therefore cannot be blended or complementary.

The realist perspective is that the world has an existence which is independent of our (human) perception (Williams & May, 1996). This suggests there is an objective truth about reality that can be investigated and measured. This philosophical approach is typically aligned to the use of quantitative methods. In contrast, constructionism suggests that there are multiple, socially constructed realities, ungoverned by laws natural or otherwise (Guba & Lincoln, 1994). This suggests that reality is subjective and therefore the [research] priority is to understand differing perspectives of reality. This approach is traditionally aligned with qualitative research methods.

Determining the nature of reality, whether it is objective or subjective, was important for this study as answering the research questions required multiple sources of evidence. In particular, the condition of dementia could be interpreted from realist or constructionist perspectives. For the realist, dementia can be understood and measured by the quantifiable changes in the structure of the brain. As these changes in the structure of the brain are observable and measureable upon post mortem examination we can say, objectively speaking, that neurodegenerative disease exists independently of social perception or social interpretation. Understanding and acknowledging these biomedical changes in the brain which impact on a patient's functional abilities is essential to adapting the healthcare system to make it more 'dementia friendly'.

However, there is also a strong argument that we must acknowledge and understand the social construct of dementia as a disability, because social environment and interpersonal interactions have an important impact on the experience of PWD (Bridges et al., 2010; Dewing & Dijk, 2014). It is

documented that patients known to have a diagnosis of dementia can be seen by healthcare professionals as having excess disability when hospitalised, and that this directly influences any interactions. For example, if healthcare staff believe it is not possible to communicate with a PWD they may choose to speak to a relative which undermines the personhood of the PWD (Bridges et al., 2010). Furthermore, PWD may be subjected to unnecessary medical procedures- such as insertion of urinary catheters to save the time associated with changing incontinence products or to reduce risk of falls- as staff perceive these interventions as appropriate while treating PWD (Fakih et al., 2010; Hwang & Morrison, 2016). These interactions, whether of a social or medical focus, play an important role in shaping a person's experience of accessing emergency care. Therefore, understanding how subjective interpretations or perceptions of 'dementia as a disability' affect a person's experience of being in hospital is an equally important element of answering research questions such as those posed here.

It is argued here that a purist approach that relies solely on one ontological perspective will fail to fully capture the experience of an ED visit for a PWD. For that reason, it is important to move beyond a two-paradigm approach and embrace a pragmatic ontology. Pragmatism rejects the idea put forward by Smith that realism and constructionism are ontologically opposed to one another and instead embraces the possibility- and in fact necessity- of blending philosophical approaches and methods in whichever way is required to best answer a research question (Johnson & Onwuegbuzie, 2013).

Embracing pragmatism is consistent with the argument put forward by Seale (2004), who believed that social scientists should not be drawn into high-level debates about the philosophical foundations behind social research if they are not essential to answering the research question. As the goal here was to improve understanding of the experience of people accessing, or providing care in ED, the priority should be ensuring high quality data collection and analysis by the most appropriate combination of methods in order to answer the research questions (Seale, 2004). This approach allows the researcher to focus

on gathering high quality, holistic data from multiple sources that might contribute to a patient-centred intervention that is fit for purpose in the various interacting systems that make up the ED.

4.2.1 Critical Realism

Epistemology is a branch of philosophy, which contemplates the origins, nature, and limitations of human knowledge, and for this research a critical realist epistemological perspective has been adopted. The development of critical realism is often attributed to Bhaskar who developed critical realism as an alternative to pure positivism, traditional realism, or social constructionism (Cruickshank, 2012). A key feature of critical realism is retention of:

> "…An ontological realism (there is a real world that exists independently of our perceptions, theories, and constructions) while accepting a form of epistemological constructivism and relativism (our understanding of this world is inevitably a construction from our own perspectives and standpoints)"
>
> (Maxwell, 2010, Pg 5).

In this study, answering the research questions adequately is dependent on the ability to recognise and acknowledge both realist and constructivist perspectives, which makes this epistemological standpoint appropriate for this research.

Furthermore, critical realism is an accepted research paradigm for health systems research. Health systems research, argues Cruickshank (2012), is not particularly well suited to either pure realism or pure social constructionism. Cruickshank (2012), quoting Bhaskar (1975/1997), argues that carrying out 'realist' research, requires a 'closed system'- such as a laboratory- where inputs and interactions can be controlled for and measured. A hospital, however, is an open system, where "unobservable causal laws interact in contingent ways to produce change at the level of observable events" (Pg. 73). The challenge with hospital-based research then is that we must acknowledge the important contribution of distinct structures and systems which exist independent of personal perception, while also understanding that the experiences of patients and staff can be influenced by their interactions with other individuals who are

present within those systems and structures. The use of critical realism as an epistemological standpoint here allows the researcher to interrogate the data collected to identify the challenges of a hospital for someone with dementia - both as they relate to these unobserved laws and contingencies in hospital systems, and the subjective experiences related to their interpersonal interactions and reactions. This final point also demands that the methods employed to collect data are sufficiently diverse to allow such interrogation.

4.2.2 Mixed methods

The use of mixed, and multiple methods is growing in popularity as social research becomes increasingly complex and interdisciplinary (Johnson & Onwuegbuzie, 2013). In order to answer the research questions here it has been essential to use a blended approach of both quantitative and qualitative methods. The pragmatist research paradigm which informs this study supports the use of multiple and mixed methods as the primary goal is to find the best combination of approaches to answer a research question (Johnson & Onwuegbuzie, 2013). The research aim has been to understand both the objective and subjective factors which impact on the safety of a patient with dementia in the hospital, and the use of mixed methods in a sequential format has enabled the researcher to triangulate data and approach the issue with a broad perspective. For example the literature review, observations, and documentary analysis have provided data about the systems in which the patients are being treated, while the survey and interviews offer an opportunity to explore how patients, carers and staff experience interactions with in these systems. Furthermore, the use of sequential design with an iterative approach has enabled identification of key issues with ED services from the perspective of service users. This then allowed for exploration of the potential individual or system factors that are contributing to the perpetuation of these issues.

4.3 Patient Safety

This section of the chapter introduces the theories and approaches to patient safety that influenced the research design and process. It begins with a definition of patient safety, and then explores the relationship between simplicity, complication, and complexity and how these concepts can be applied to the evolution of patient safety. An argument is then presented for why it is most appropriate to treat the challenges posed by caring for PWD in ED's as complex problems. It concludes with an argument for why adopting a human factors approach was most appropriate for this research and the rationale for using the Yorkshire Contributory Factors Framework.

Safety is one of the core priorities in the provision of healthcare. The intention to ensure safety is embodied in the Hippocratic oath which states "primum non nocere" or "first do no harm" (Kinsinger, 2010). The World Health Organisation (WHO) defined safety in 2009 as "*the avoidance, prevention, and amelioration of adverse outcomes or injuries stemming from the processes of health care…These events include "errors", "deviations" and "accidents*" (Bates, 2010, Pg14). However, despite a concentrated effort to improve safety, adverse events in healthcare are still a leading cause of death and disability. In the NHS, approximately 10% of hospital admissions result in an adverse event where the patient experiences harm- around half of which are thought to be preventable (Department of Health, 2000).

Over the past 30 years there has been a fundamental shift in how we think about and measure patient safety. Traditionally patient safety (improvement) programs have focused heavily on identifying and correcting erring individuals whose actions had led to patient harm. Gawande (2002) explains this as the belief that "good health care" is the result of competent people performing tasks to a high standard. For those who hold this belief, it therefore follows that "bad healthcare" must be the result of human ineptitude. Within this belief system 'safety' is conceptualised as a straightforward problem with easily identifiable cause and effect relationship between individuals' actions and patient harm.

The perception that medical error is the result of a competency problem relies on a 'simple' understanding of the causal pathways of patient harm. Glouberman and Zimmerman (2002) define simple problems as ones where the causal relationships are known, singular, and linear. They further note that once a solution to a simple problem has been found it can be applied universally to that problem in the future, and its application carries a strong likelihood of success. It is now widely accepted that the traditional 'find and fix' approach has not succeeded in delivering the positive improvements in patient safety that were expected (Bones et al, 2010; Shojania & Thomas, 2013). It became clear that a more nuanced approach to patient safety (and quality improvement) was required.

At the turn of the millennium a new approach to thinking about patient safety began to emerge. The report "To Err is Human" from Donaldson, Kohn, and Corrigan in the USA (2000) and the Department of Health report "An Organisation with a Memory" (2000) marked a fundamental shift in thinking about the nature of preventable harm. Rather than focusing solely on individuals and errors, these reports encourage a shift towards thinking about safety as a whole health systems problem. A 'system' is defined by Chapanis (1996) as "*an interacting combination, at any level of complexity, of people, materials, tools, machines, software, facilities and procedures designed to work together for some common purpose*" (Pg. 22). The table below taken from Dekker (2011, pg 45) highlights some of the key differences between " the old view" and the whole systems view which is a central premise of the "human factors approach" to safety. Column one represents the "the old view" and column two represents a human factors approach to thinking about patient safety.

Figure 10: Two Views of Human Error

1) Human error as a medical competence problem	2) Human error as an organizational problem
Human error is a *cause* of trouble	Human error is a *symptom* of trouble deeper inside the organization
Human error can be the conclusion of an investigation	Human error is a starting point for deeper investigation
Human error is itself a useful target for intervention	Meaningful intervention lies in the factors that help produce human expertise and error
Healthcare is basically safe: it needs protection from unreliable humans	Healthcare is not inherently safe. Only people can create safety by reconciling multiple goals, pressures, constraints, and complexities

The human factors approach emerged from the burgeoning field of ergonomics in the aftermath of World War Two. While its origins emerged from engineering- in particular aviation engineering- its application to healthcare became apparent once the discipline widened its purview to focus on any situation in which errors can occur. Chapanis (2004) in Dekker (2011) explains that the human factors approach encourages the questions "*What is there about the system that allows a person to commit an error*?" and "*How could the system be changed or redesigned so that it would be difficult or impossible for even fallible humans to make mistakes*" (Pg.37).

This shift in thinking represents an emergent understanding that patient safety cannot be conceptualized as a simple problem, but rather must be understood as a complicated problem. Gloubermann and Zimmerman (2002) describe 'complication' as problems that have multiple components, and may have multistep causal chains. They may contain multiple simple problems, but the solution cannot be found by simply reducing the larger problem to the various simple components and addressing them in isolation. Addressing complicated problems requires a comprehensive understanding of the multiple components that feature in the problem, the casual relationships that create the problems, and the way those problems interact with each other.

In 2005 the WHO released their report on the World Alliance for Patient Safety: Forward Program 2005. This report strongly aligned the WHO Patient safety program with the human factors approach, it states

> "Current conceptual thinking on the safety of patients places the prime responsibility for adverse events on deficiencies and system design, organization and operation rather than on individual providers or individual products. Similarly, most adverse events are not the result of negligence or lack of training, but rather occur because of latent causes within the system. For those who work on systems, adverse events are shaped and provoked by "upstream" systemic factors, which include the particular organization strategy, its culture, its approach towards quality management and risk prevention, and its capacity for learning from failures. Countermeasures based on changes in the system are therefore more productive than those that target individual practices or products. Safety is a fundamental principle of patient care and a critical component of quality management. Its improvement demands a complex, system wide effort, involving a broad range of actions in performance improvement, environmental safety and risk management, including infection control, safe use of medicines, equipment safety, safe clinical practice, and safe environment of care. It embraces nearly all health care disciplines and actors, and thus requires a comprehensive, multifaceted approach to identifying and managing actual and potential risks to patient safety in individual services and finding broad long-term solutions for the system as a whole. Thinking in terms of "systems" offers the greatest promise of definitive risk reduction solutions, which place the appropriate emphasis on every component of patient safety, as opposed to solutions driven by the narrower and more specific aspects of the problem, which tend to underestimate the importance of other perspectives
>
> (World Health Organisation, 2005).

The human factors approach prioritizes identifying the sources of safety and risks to patients across all levels of an organization, by considering the interaction between people and systems, from activities at the sharp end of practice to the latent conditions, often generated by management and external factors such as government policy.

In recent years, the human factors approach has been growing in popularity (Carayon, Wetterneck, et al., 2014; Carayon & Wood, 2010; Dekker, 2005, 2011; Gawande, 2010; Reason, 2008; Rosenorn-Lanng, 2014). The growing popularity of human factors may be explained in part by its ability to

identify pre-conditions for errors that makes it possible to intervene earlier. There are two main strategies to reducing medical error- proactive and reactive (Lawton et al., 2012). According to Lawton (2012), the reactive approach "*relies on learning from (reacting to) previous incidents to minimise error in the future*" while the proactive approach is *"concerned with prospectively identifying the latent failures within organisations that represent the preconditions for errors, and addressing these before a serious event occurs*" (p369). Therefore, adopting a human factors approach has the capacity to pro-actively prevent patients from experiencing harm.

Glouberman and Zimmerman (2002) argue that one of the major issues with healthcare research is that it continues to treat problems as 'complicated' when in fact they should be considered 'complex'. As noted above, complicated problems are ones that have multiple components, and may have multistep causal chains. Furthermore, complicated problems may contain multiple simple problems, but the solution cannot be found by simply reducing it to the component simple problems. In comparison, complex problems also have multiple components, but are not reducible to their constituent parts, and the causal pathways are often adaptive or may not be understood or known (Glouberman & Zimmerman, 2002). While addressing complicated problems requires a comprehensive understanding of the multiple components that feature in the problem, the causal relationships that create the problems, and the way those problems interact with each other, it is still possible to apply solutions to complicated problems universally. Addressing complex problems, however, requires an additional understanding of unique local conditions (Stacey, 1992) , ability to understand the interdependency of the constituent parts when the causal pathways may be non-linear (Holland, 1995; Lorenz, 1993) and an ability to adapt as conditions change (Kauffman, 1995; K. Kelly, 1994).

It is argued here that ED' are by nature complex. This is due to the requirement to adapt continually to the emergent and dynamic needs and priorities of patients. Furthermore, as many PWD are older adults who live with

chronic conditions, the care they require in the ED is also likely to be complex. Glouberman and Zimmerman explain the difference between 'complicated' acute disease, and 'complex' chronic disease.

Figure 11: Complicated Acute Diseases and Complex Chronic Diseases

Complicated Acute Diseases	**Complex Chronic Diseases**
Abrupt onset	Gradual onset over time
Often all causes can be identified and measured	Multivariate cause, changing over time
Diagnosis and prognosis are often accurate	Diagnosis is uncertain and prognosis obscure
Specific therapy or treatment is often available	Indecisive technologies and therapies with adversities
Technological intervention is usually effective: cure is likely with return to normal health	No cure, pervasive uncertainty: management, coaching and self- care over time is needed to improve health
Profession is knowledgeable while laity is inexperienced	Profession and laity must be reciprocally knowledgeable to improve health

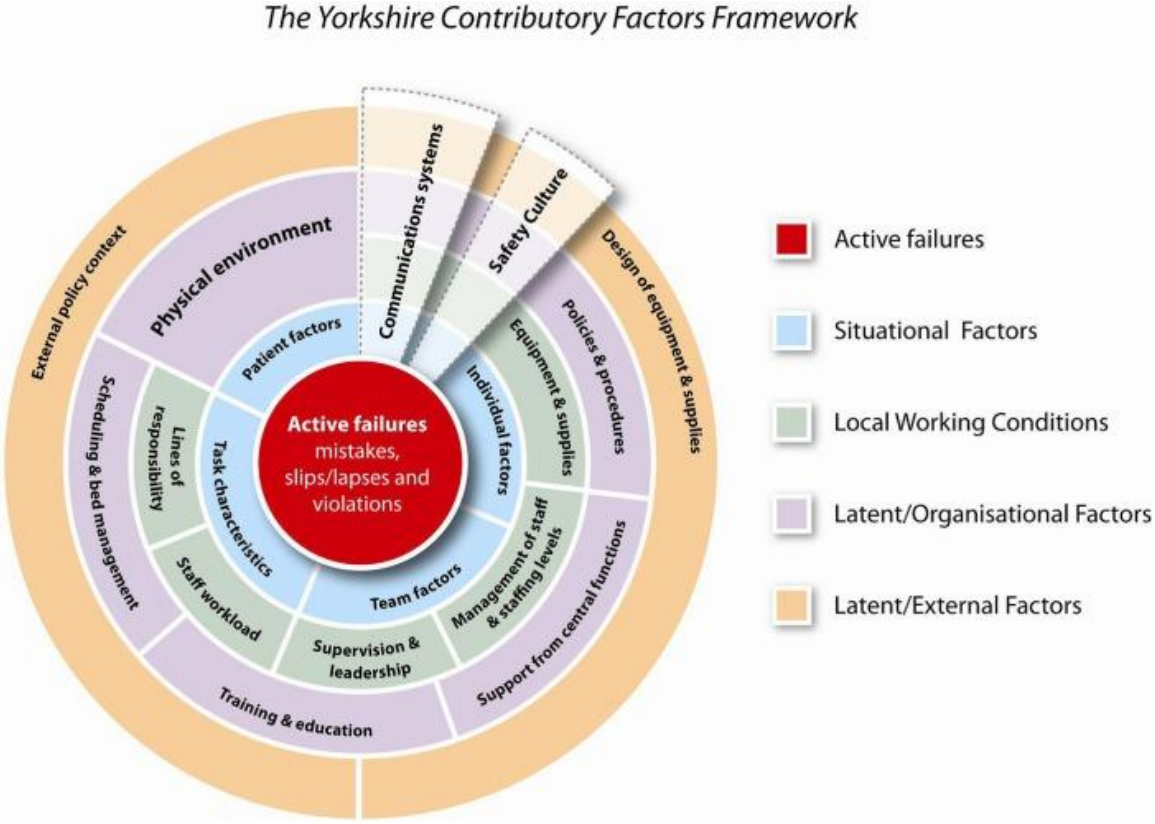
(Table taken from Glouberman & Zimmerman, 2002, Pg.9)

Given the complexity of both the location of this research, and the potential participants, it was imperative to find a theoretical framework that could adequately address the multiple, constituent elements of the experience, and explore flexible investigation of the relationship between these elements. To maintain academic rigor and offer structure to particular elements of the data collection process, the researcher sought an existing framework that was aligned with the human factors approach to thinking about patient safety.

Consequently, the Yorkshire Contributory Factors Framework (YCFF) was chosen as a theoretical model to guide inquiry, and an adapted version of the model was used as an interview guide (*see chapter seven for detail*). The YCFF was developed using a comprehensive literature review of 95 publications, describing 83 studies, undertaken in November 2010. Papers were included in the review if they identified contributory factors to active

failures, or reported a framework of organizing contributory factors, and were based in acute or secondary care. The aim of this review was to produce a clearly defined and hierarchical framework of empirical evidence that describes contributory factors that can have an impact on patient safety in hospital settings (Lawton et al., 2012). The resulting framework includes both proximal (sharp end) and distal (latent) factors. The use of this tool here has enabled the exploration of multiple potential contributory factors and the complex relationships between them that can influence the safety and quality of care for PWD in the ED.

Figure 12: The Yorkshire Contributory Factors Framework



An additional benefit of using the YCFF as a theoretical framework was that it enabled exploration of both negative and positive experiences of care,

although its proposed use was for patient safety incidents only (Lawton et al, 2012). Given that the task of improving care for PWD is a complex task, finding an approach to quality improvement that can appropriately address that complexity is paramount. One solution to this challenge is by seeking out practices that have already been used successfully. Asset-based problem solving is an alternative to traditional organisational problem solving that relies on identification of a problem, followed by proposing a solution (McClean, 2012). In contrast, asset-based problem solving identifies a mutually desired outcome, and then considers what assets exist within the organisation that could be leveraged to achieve that outcome. This approach is widely used in community development initiatives, but its value in addressing challenges in healthcare is becoming more widely acknowledged (Boyle, Connisbee, & Burns, 2004). At its core is the belief that the knowledge and skills required to create and sustain effective change can be found within the organisation. One way of identifying these assets that can support change is by identifying positive deviants.

The positive deviance approach is based on the premise that "*in every community there are certain individuals whose special practices, strategies or behaviours enable them to find better solutions to prevalent community problems than their peers who have access to the same resources*" (Devane, 2009, Pg 3). Positive deviance has also become a popular methodology in patient safety research, as it offers an alternative to traditional retrospective evaluations of adverse events (Lawton et al., 2014). Traditional approaches have not succeeded in creating significant improvements in patient safety as interventions to improve safety are developed in response to retrospective evaluation. Therefore, they frequently failed to be widely adopted (Bones et al, 2010; Shojania & Thomas, 2013). By comparison, positive deviance seeks to identify examples of when things go well despite complex and often challenging circumstances. Lawton et al (2014) note, "*behaviours that produce errors are variations on the same processes that produce success, so focusing on successful practices may be a more effective tactic*" when trying to create

lasting improvement (Pg1). Using this approach it is possible to identify established good practices, and use those to create interventions which are locally owned, readily accepted, and feasible within the resource constraints, something which is especially helpful in cash-strapped services such as the NHS.

This section has introduced the theories and approaches to patient safety that influenced the design and process of this research project. It has given a brief history of the evolution of thinking about patient safety- noting the shift away from the perception of medical error as a the result of individual human competency or error and towards a systems approach to thinking about safety. The importance of recognizing the difference between complicated problems has been introduced, and an argument presented as to why dementia in ED must be considered as a complex (patient) problem. From this the rationale for adopting a human factors approach- in the form of the Yorkshire Contributory Factors Framework- was offered. This section concluded with an argument as to why asset-based problem solving- in the form of seeking positive deviants- is an appropriate approach to addressing the complex challenge presented by attempting to improve the quality and safety of care of PWD.

4.4 Participation of people with dementia

A core belief underpinning this work is that people with all stages of dementia can make meaningful contributions in research and must be supported and enabled to do so wherever possible. There is a growing recognition that PWD are under-represented in research about their condition. This underrepresentation persists despite guidance developed by the Scottish Dementia Working Group Research Sub-group highlighting the importance of ensuring PWD are supported, enabled, and encouraged to participate in research and shape health services if they are interested in doing so (Scottish Dementia Working Group, 2014). Including PWD in research is still considered a relatively novel concept, and the majority of research relies on carer responses as a proxy measure of ‘patient’ experience. Recently there has been

an increasing understanding of the importance of including PWD in research and this is being reflected in policy and practice. An example of this new commitment to involving PWD in research can be found in the National Dementia Declaration (2016), developed by people living with dementia in conjunction with the Dementia Action Alliance and the Alzheimer's Society. This document includes the statement *"We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia, and be supported to take part*". This new commitment to including PWD in research is associated with the "rights based" model of dementia care that is being championed in the UK (Kelly & Innes, 2013).

This commitment to involving PWD as active and autonomous participants in every stage of the research came with an ethical imperative to ensure the research was conducted in ways that was both accessible and minimized risk to participation. The Helsinki Declaration on Ethical Research Practice (1964) declares autonomy, beneficence, justice and non-maleficence as cornerstones of conducting research, and these principles guided decisions on methods and approaches throughout this research.

Kinsinger (2010) defined beneficence as the commitment that "*practitioners are to act in a way that contributes to the patient's health and well-being and to take care to refrain from doing anything that would cause harm*" (pg44). This principle played an important role in making the decision to include PWD as autonomous participants. PWD are far more likely than their age matched peers to experience avoidable harm while they are in hospital (Tsilimingras et al., 2003). There is therefore an urgent need for interventions that can address the systemic contributory factors that are causing this potentially vulnerable group of patients to come to harm. However, as this is non-therapeutic research, there was no potential for direct benefit to participants. The primary benefit therefore was the opportunity to contribute to a research project that could shape and improve services in the future. In order for this research to have a significant and beneficial impact on practice, it needed to be representative of the full patient cohort, and therefore we felt it

was essential to ensure that the opportunity to participate was extended to all potentially interested participants.

Understanding the current experience of care from the perspective of the patient is a vital step in identifying those barriers to safety. As dementia is progressive disorder, excluding PWD- who may or may not have legal capacity to consent- would disproportionately affect individuals with moderate to severe dementia, who are already highly underrepresented in health service research. It was therefore felt that there was an ethical obligation to ensure PWD of all stages were supported and enabled to participate if they so desired to maximize likelihood of benefit to participants in the future.

However, while it was essential to gather the stories and experiences of people who have experienced a visit to ED, that need had to be weighed against the potential risks to the participants. The principle of non-maleficence is defined as "*active avoidance of any act that could cause harm*" (Kinsinger, 2010, Pg45), and ensuring the participants were not exposed to undue harm or distress as a result of their participation was another key factor in determining which methods and approaches to use. The key risk of harm in this research project was the potential for participants to experience emotional distress, either as a result of reflecting on potentially traumatic events or distress stemming from an inability to recall.

It is known and understood that the period immediately preceding, and during a hospital admission can be a time of significant stress and emotional turmoil for PWD and their families. While we did not expect participation to have an undue risk of causing distress, the potential for inadvertent harm was recognized. The desire to ensure participants were protected, while also encouraging participation, led to the creation of comprehensive processes of assessing capacity, collecting consent, and direction to post- participation support mechanisms. In addition, the need to minimize distress impacted the methods and tools that were used to collect data in both stages of the research. For example, when choosing the platform to host the online survey, Bristol Online Survey (BOS) was selected over Survey Monkey because the BOS

offered the option of closing the survey and returning to it at a later date without losing data. It was felt this option was important as it allows participants the freedom to engage with the survey when they felt able to complete, and gave the option of taking a break in the event of experiencing distress.

From the outset of this project, it was understood that dementia is a progressive condition that almost always impacts the affected person's ability to recall events. It was felt that it could be distressing for PWD to be asked about events they may not be able to recollect. In preparation for this research the researcher undertook an investigation on best practice in supporting recall. There is currently a considerable gap in the literature on involving PWD in research that involves recall, and further research is needed to determine the most effective ways of facilitating this knowledge elicitation. After discussion with an expert panel who advised on this project, we determined that the potential risk of distress related to inability to recall could be reduced by using an interviewing approach called cognitive interviewing which has been shown to support respondents to recall information more easily and accurately. See chapter seven for additional detail on the process and application of how cognitive interviewing was used in this project.

In conclusion, the research team felt strongly that it was essential we selected methods that would enable the voices of PWD to be kept at the forefront of this research project. This commitment to supporting and enabling participation came with an ethical duty to ensure that the level of risk that participants were exposed to was commensurate with the non-direct, potential benefit to the overall patient population. In practice, this commitment to facilitating participation had an impact on which methods and approaches were used. For further detail on the methods that were used, and a discussion of the practical steps that were taken at each stage to safeguard the participants, see chapters five (quantitative methods) and seven (qualitative methods).

Methods: Phase One

5.1 Purpose and outline

This chapter will provide a comprehensive description of the specific steps involved in the development, administration, and data analysis of the survey employed in Phase One of this study. As stated earlier, this is a sequential study; Phase One (survey) data influenced the development and administration of the Phase Two qualitative study.

The first section of this chapter discusses the methods used including the rationale for using a custom designed survey, and a discussion of why co-design was used to facilitate this custom design process. The co-design process is then explained in detail, and a discussion of the piloting and validation process is presented. This is followed by a description of the recruitment and dissemination strategy. This section concludes with a reflection on the recruitment challenges that delayed this phase of research, and a justification for the adapted geographical scope of the research that was eventually adopted to address the issue. The chapter concludes with a discussion of phase specific ethical issues; including the administration of a survey without written consent, and the rationale for excluding participants who could not complete the survey in English

5.2 Survey

The aim was to retrospectively examine the experiences of PWD and the carers who support them during an unscheduled admission to hospital via the ED. In particular, the survey aimed to explore the experience of arriving at the hospital, triage, diagnosis, and treatment and care, and the interactions between PWD, their carers and ED staff.

The survey objectives were to;

1) Identify the aspects of care in ED which PWD and carers consider most important to provision of dementia friendly care
2) Identify particular elements of the patient pathway through ED that are highlighted as posing a challenge for PWD.

3) Understand the relationship between particular aspects of care and self-reported satisfaction with the experience.

The data collected through this survey also helped to identify practices or approaches that warranted further investigation in the subsequent qualitative phase of the study.

A self-administered survey was distributed to PWD and carers in England. The survey consisted of 39 closed response items in the form of Likert scales, and a final question allowed respondents to share thoughts in free text form. The survey is separated into seven sections:

1) Information and Consent
2) About you
3) About the admission
4) Triage and Assessment
5) Treatment area
6) Staff
7) Communication
8) Suggestions on how to improve ED's for PWD (free text)

The survey was administered in a dual online or paper based format. The online survey was hosted by Bristol Online Surveys (https://www.onlinesurveys.ac.uk).

5.3 Justification of methods

5.3.1 Survey method

A survey method enables the researcher to gather data from a large number and wide variety of respondents. This data could then be used to focus on issues that service-users felt were important, and inform the research questions for Phase Two.

After determining that a valid standardized measure appropriate for this research did not already exist, a modified Delphi approach was used to create a custom-designed survey tool. This method was chosen as it has been demonstrated to be an effective method of facilitating a process of informed,

collective judgement for survey development when prior validated measures do not exist or are not appropriate to context (Ramim & Lichvar, 2014).

There are several benefits to using a survey method. A survey is a cost-efficient and expeditious means of gaining a cross section of anonymised views from a large sample of the target population who have the opportunity to give a candid response (Truell, 2003). Furthermore, as this was a doctoral project with limited budget, a survey was an appealing option for gaining a large seam of data from a wide geographical area, with significantly less time and resource allocation compared to face-to-face data collection. Moreover, using a multifaceted recruitment strategy offered a diverse array of potential respondents, who may not be traditionally research active, the opportunity to participate. Finally, the survey method allowed researcher to continue with the setting up of Phase Two and to complete other work while the survey was in the data collection stage.

However, there are some disadvantages to using a survey method that cannot be ignored. The recruitment methods for this survey, which did not employ a randomized sample means that there was a risk of selection bias. The people who chose to participate may do so because of a particularly notable experience in hospital (positive or negative), thus the survey may fail to capture a full and representative range of experiences (Eysenbach, 2004). While this is an accepted risk of convenience sampling, random sampling was not feasible here given time and budgetary constraints. After careful consideration, it was decided that the use of multiple recruitment portals across several communities should counter this potential bias to an acceptable extent. Furthermore, it was hoped that this approach would motivate potential participants who might not routinely self-select without encouragement from awareness raising via knowledge of their peer's participation.

There was a further risk that the online version of the survey would fail to reach a sufficiently representative sample, as many PWD are older adults, and many carers are spouses. There is a trend towards increasing internet usage amongst adults 65 and over, however, some older adults lack confidence in

using social media and web-based communications (Zickuhr & Madden, 2012). In the UK, over 60% of people aged 75 or older do not routinely use the internet (AGE UK, 2016) Time consideration and budget prevented the survey from being entirely paper-based. As a result, the decision to use dual online and paper based formats was taken. This capitalized on the ease and cost effectiveness of an online platform while also enabling a broader scope of participation from those who may not be confident with, or routinely exposed to, online platforms. While there were budgetary implications associated with printing paper surveys and providing pre-addressed envelopes, this was a fraction of what the total cost would have been if the entire survey had been paper based.

Finally, the survey method always carries the risk of a low response rate. This was a notable challenge in this project- and the steps taken to address the initially low response rate are discussed in the section on recruitment (5.5.4.2) below.

5.3.2 Co-design

Over the last 20 years, there has been a shift in how patients are involved in the delivery and design of services. The perception of patients as passive recipients, or consumers of care has been challenged, and in its place the idea of patients as active contributors and co-producers has emerged (Doherty & Mendenhall, 2006). There are a multitude of ways to involve patients and public in the design and delivery of health services. One way to measure the relative levels of engagement is using Arnstein's ladder of citizen participation (1969) which is still considered a touchstone for service-user involvement (Capstick et al., 2016). This ladder sets out levels of engagement ranging from inauthentic and tokenistic gestures- i.e. informing, consulting, and placating- to authentic and empowering programs which are citizen led-i.e. citizen control, delegated power, and active partnerships (Arnstein, 1969).

Using this model, it is possible to chart the slow but steady trend in increasing patient involvement in the design and delivery of health services in

the UK (Wanless D, 2002; Boyle, Connisbee, & Burns, 2004; Crisp, 2005; Darzi, 2008; Department of Health, 2010) This change in attitude has been reflected at the policy and strategic level where there has been a commitment to redesigning systems and participatory frameworks to ensure citizens are located alongside health care staff in development plans (Bate & Robert, 2006; Darzi, 2008; Department of Health, 2005). However, even with these attempts to embed participatory frameworks into system design, emphasis on patient involvement is constantly challenged by the scarcity of resources available to facilitate substantive involvement and the limited capacity of staff who are often juggling multiple responsibilities.

Co-design has been used in a variety of industries as a means to improve the output of design processes. The process typically involves bringing together a diverse group of experts - either professional or experts by experience - to co-operate creatively in the development of new approaches or products (Steen, Manschot, & Koning, 2011). In healthcare research, co-design is a way of bringing staff, patients and carers together to design services which improve the experience of patients and are fit for purpose by the staff who need to use them (Boyd et al., 2012). This approach has been used in a variety of projects relating to the design of dementia services including research by Hunter et al (2016) and Tan & Szebeko (2009) and in patient safety (O'Hara et al., 2016).

There are several benefits to co-design which include creative idea generation through the sharing of knowledge, increased speed of adoption of interventions due to local ownership, development of interventions which accurately reflect user experience, increased user satisfaction with services, and lower costs for the organisations implementing the interventions (Steen et al., 2011). A key priority of this project was ensuring that the custom designed survey was an accurate reflection of the lived experience of PWD and family supporters and the use of co-design in survey development facilitated this.

5.4 Design

5.4.1 Co-production of survey

To ensure the design of this survey was appropriate and accessible to the potential participants, and that the content was relevant, an expert advisory panel was convened in April 2016. The panel had an active role in overseeing the design and validation process. The three experts by experience reflect the three main participant groups in this research.

The panel was chaired by the researcher and consisted of:

1) **Expert by experience**-Former NHS staff development officer and person living with dementia
2) **Expert by experience**-Former Community Nurse/Care Home proprietor and family carer
3) **Expert by experience**- Admissions avoidance Matron, specialising in dementia in acute care
4) **The lead supervisor-** A patient safety expert who has experience of co-design
5) **Co- supervisor**- An expert on innovative research methods to facilitate participation of people with dementia
6) **Method advisor**- Academic expert in survey design

The preliminary content of the survey was informed by a narrative literature review that highlighted previously identified issues of patient safety and quality of care for people with dementia (see pages 18-28 for details). While there is a paucity of published research on the specific issue of safety and experience of care in the ED for PWD, there is a large body of associated information on older people's emergency medicine, ward-based care for PWD, retrospective studies investigating causes of caregiver dissatisfaction with emergency care, and training on best practice standards for staff working in ED's.

For the purpose of the survey, the literature was organised into broad themes: experience of admission; physical environment of the ED; experience of receiving medical care in hospital; relationships with healthcare staff; carer involvement during the admission; impact of staff levels and attitudes; and communication. These themes were then presented as mind maps to the expert panel. The panel supplemented this literature with input based on their experience of acute admissions as service users and stakeholders. These two data sources- the literature and the expert input- were the origin of the survey's contents. For a chart detailing the literature sources and contribution of the expert panel to development of each of the survey domains, please see appendix four.

5.4.2 Delphi method

The Delphi method is described as "a group communication process that aims to achieve a convergence of opinion on a specific real-world issue" (Hsu & Sandford, 2007). This method typically uses multiple iterations of feedback based on a systematic process to enable a select panel of experts to share opinions with a researcher and each other and eventually reach consensus. This project was constrained by time and budgetary considerations and therefore was informed by the Delphi principles rather than a pure interpretation of the method, i.e multiple iterations of feedback to reach consensus.

The process for this project consisted of two face-to-face meetings with the full expert panel and opportunities to provide feedback privately to the researcher between the meetings.

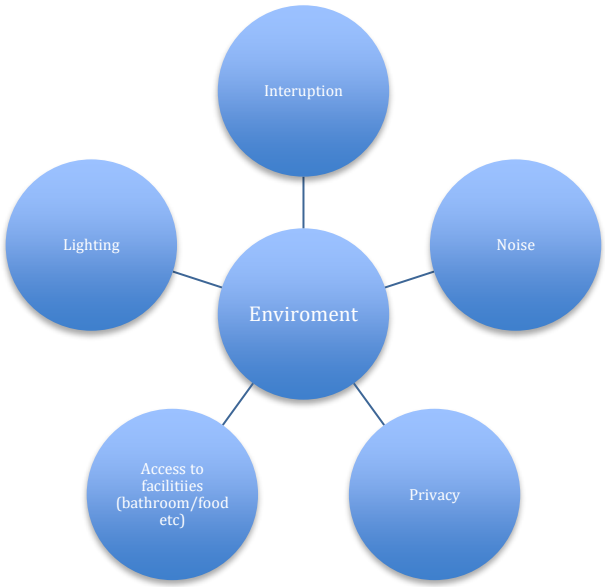
5.4.3 Process of development

For a chart showing the process of development, see appendix five.

The first meeting of the expert panel was held on April 19th, 2016. At this meeting the panel reviewed the survey aims; inclusion and exclusion criteria; sampling strategies, and discussed how the issues identified in the literature aligned with lived experiences. As noted above, prior to the meeting, issues that

were raised in the literature were organised into broad themes and then displayed as simple mind maps (See figure five below for an example). The expert panel reviewed these mind maps for accuracy, and added their reflections. At the conclusion of the meeting, the expert panel concluded that the collaboratively edited mind maps were an accurate reflection of the real world issues faced by PWD and carers in ED.

Figure 13: Sample Mind map



Following this first meeting, an initial draft of the survey was developed and circulated to the expert panel, who reviewed the content, language, accessibility, and formatting of the preliminary design. This iteration of feedback was done privately, either through e-mail or private phone call based on the preference of the individual panel member. The benefit of private feedback iterations, is 'subject anonymity' which can counteract the effect that dominant or vocal individuals may have in the group meeting setting and enable all members of the group to provide their feedback (Hsu & Sandford, 2007). However, with this approach there is always a potential for conflicting feedback to be received that can complicate the editing process. Where members of the expert panel expressed opposing views, the item was flagged as a priority for discussion at the next meeting. Examples of changes that were made in this

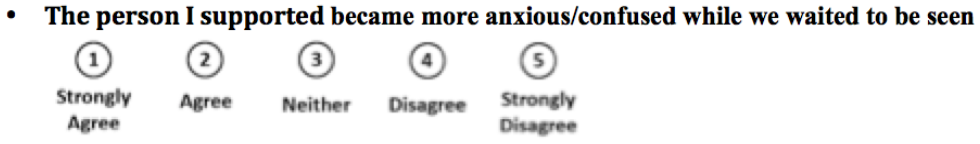
first round of editing included streamlining the information and consent process on the first page, correcting a programming issue which streamed participants to the incorrect versions of the survey, and editing the wording of several questions to reduce ambiguity.

Feedback was synthesised and an updated draft was recirculate in advance of the second meeting held on May 12th 2016. In the second face-to-face meeting panel members discussed each item on the survey line by line and further changes were made to the layout.

Various approaches to survey layout and design were considered by the expert panel. The primary consideration was how best to display the questions and response options to minimize confusion and maximize opportunity for PWD to engage meaningfully with the content. As the researcher was undertaking analysis alone, the time required to clean and analyze the data was a key consideration. Ultimately the panel determined that closed response questions would create the best breadth of response without overwhelming a single researcher with unmanageable amounts of data. These closed response questions were presented as Likert scales.

Visual analogue scales with a range of facial expressions were considered, but ultimately rejected after members of the expert panel expressed concern that visual analogue scales may be confusing for PWD. The final version of the survey has each response option- strongly disagree, disagree, neither agree or disagree, agree, strongly agree- written out in full for each question. This was determined by the expert panel to be the clearest way to denote response options. When completing the survey participants were asked to select which response best represented their reaction to a given statement

Figure 14: Sample Survey Question



Two versions of the survey were created- one for PWD and one for carers. The content of these surveys is almost identical with only minor adaptations in language to reflect the identity of the respondent- see appendices six and seven for copies of the final surveys. Based on feedback from the expert panel, the layout of the survey for PWD has several additional features such as large question numbers to assist with signposting throughout the survey, and an introduction section at the top of each page to assist with context reinstatement. These adaptions are designed to maximize usability and accessibility of the survey for PWD.

In principle, the design, content, and layout of the survey were agreed in at this meeting. However, the final version of the survey was not confirmed until updated versions- both paper and online-were circulated to the panel members for review and sign off.

5.4.4 Testing the survey

Following expert panel sign off for the online and paper versions, the survey was piloted with a small cross section of respondents recruited via the larger Faculty of Health Sciences *Experts by Experience Panel* at the University of Bradford. The first stage of the testing process consisted of a 'think aloud' interview (French et al., 2007). For this phase of testing, four participants (two PWD and two people who were former or current carers) were invited to complete the survey at the University and "talk through" their thoughts and experience with the researcher as they completed the survey. This process was used to assess usability and face validity. This round of testing highlighted an issue of ambiguous wording in two questions that caused confusion for respondents. The first question that caused confusion was about the age of the participant. The feedback from the participants indicated that it was unclear if the question was asking for the age of the patient or the age of the respondent answering the survey. The second question that caused confusion was regarding the arrival at the hospital, which also raised a question of whether the question was directed towards the patient or the respondent answering the

survey. These two questions were adapted in light of the feedback from testers and the updated version of the survey circulated again to the expert panel.

The second stage of piloting was a test-retest process that involved ten participants who had no involvement in the development of the survey, recruited through professional and personal networks. These volunteers included spouse partners, the children of PWD, and PWD. The test-retest process involved these volunteers completing the same survey twice, two weeks apart to test consistency of responses. Using this process it is possible to determine the reliability of the tool to adequately capture users' experience (Williams, 2003). The survey tested well during this stage of piloting, with 80% of respondents giving the same answer despite the time lag between the two testing dates. Where there were discrepancies in response, the majority were participants changing their response from a strongly agree or strongly disagree option, to the co-responding agree or disagree option or visa versa. This indicates that the response is likely still reflective of their overall experience[1](Fowler, 1995).

5.4.5 Validity and reliability

Validation of this tool is linked to the rigorous consultation and design process that ensured the face and content validity of the tool. The first step in ensuring validity was the convening of an expert panel to review the content of the questionnaire. This panel was reconvened to provide commentary and advised on the drafted version of the questionnaire, in particular advising on the usability and language. Usability and content validity was tested with four respondents in the 'think aloud' process ensuring the concepts being measured are clearly defined. Reliability was assessed using the test-retest approach.

[1] Fowler (1995) proposes that the selection of 'strong' may suggest an emotional, rather than cognitive reaction to a survey item. With this considered, it is reasonable to assume the experience being reflected on remains constant, but the respondents emotional reaction to the item varies for personal or situational reasons.

5.5 Sample

This section describes the sample population to which the survey was administered.

5.5.1 Eligibility

To be eligible to complete this survey, potential respondents must have been;

1) Living with dementia, or
2) Actively involved in an unpaid supporting role for a PWD

Additionally, survey respondents must have had experience of at least one admission to hospital- either as the patient, or in a supportive role- within the prior 24 months. The eligibility criteria were clearly stated on the participant information sheet that preceded the survey.

5.5.2 Inclusion

Individuals were included in this study if they returned the completed survey within the open period and were determined to have met the eligibility criteria. Surveys that were returned partially complete were included (N=6).

5.5.3 Exclusion

Individuals who were not living with dementia, or have not been in an active caregiving role for someone living with dementia, were not eligible to participate in this research. Individuals who experienced a hospitalization outside of England were excluded as the ethical approval for this study only covered sites in England. Individuals who were unable to communicate without the assistance of a translator in English were excluded from this study. It was not feasible to translate the survey into multiple languages. Refer to section 5.9.3 below for further explanation of the justification of this exclusion criterion.

5.5.4 Sample size calculations

This survey relied on convenience sampling.

5.5.4.1 Initial

Initial sample size calculations were done on the basis that the survey responses would be limited to the single geographical area of Hampshire. This was later expanded to be open to anywhere in England due to low returns. See section 5.5.4.1 for additional details on the recruitment challenges and decision to expand the inclusion criteria. Initial sample size calculations were completed using the 2013 Joint Strategic Needs Assessment done by Hampshire County Council that estimated that there are 18,000 people living with some form of dementia in Hampshire. We assumed for the purpose of this research that PWD and their carers can be considered as a unit, where one member of that partnership would respond, and therefore the total population was determined to be 18,000. Assuming a confidence interval of +/-5%, and a confidence level of 95% the initial minimum sample size was calculated to be 376 using the formula

$$\frac{\frac{z^2 \times p\,(1-p)}{e^2}}{1 + \left(\frac{z^2 \times p\,(1-p)}{e^2 N}\right)}$$

5.5.4.2 Modified

Due to poor recruitment and slow rate of return, in February 2017, the decision was made to expand the inclusion criteria to include all hospitals in England. This was deemed a minor amendment to ethical approval and notice was submitted to the NHS Research Ethics Committee who initially approved the research (See Appendix 8). The research committee accepted this amendment and the research proceeded with an expanded geographical remit. As a result of this amendment the sample size was recalculated. Recent calculations based on epidemiological data from the Alzheimer's society indicate there are around 850,000 people with some form of dementia in the UK (Alzheimer's Society, 2014). Assuming, as above, that PWD and their carers

can be considered as a unit, the total population was calculated as 850,000. Maintaining confidence interval of +/- 5%, and confidence level of 95%, the new minimum sample size was calculated as 384, again using the prior formula.

5.6 Recruitment

This project employed a multi-faceted recruitment and dissemination strategy involving partnerships with local charitable organisations and professional networks, use of the '*Join Dementia Research'* platform, promotion on social media, and public engagement sessions. As a result of this recruitment and dissemination strategy it was not possible to calculate a rate of return for the online surveys. (See appendix 9 for copy of a promotional flysheet)

5.6.1 Charitable partnerships

During the set up and recruitment phase of this research, several charitable organisations who have regular contact with older people were approached as potential partners. These organisations received an e-mail from the researcher requesting assistance with recruitment for survey research, and positive responses were followed up with a phone call or further e-mail exchange to provide additional detail. The goal of these partnerships was to maximize the avenues of dissemination for the survey and increase the likelihood that people who are not traditionally research active would be exposed to the survey. These organisations included those with a broad scope including national and regional Alzheimer's society organisations, the Carers Trust, Dementia Action Alliance, and Admiral Nurses, as well as a number of smaller regional and local organisations. To maximise likelihood of getting responses from PWD, organisations that actively involve activism by PWD such as the Dementia Engagement and Empowerment project (DEEP) and Together in Dementia Everyday (TIDE) were approached via personal and professional networks rather than e-mail.

Where it was feasible, promotional materials including flysheets and paper copies of the survey were taken by the researcher to the organisations in

person. However, this was not always feasible given time and budget constraints, and where a personal visit wasn't possible materials were mailed to a named contact at the organisation and followed up with a phone call.

These partners assisted with survey dissemination in a number of ways including sharing the online link to the survey in e-newsletter updates, sending a link to the survey in an e-mail to service users, making paper copies of the survey available in offices and at events, hosting 'survey completion events' where staff supported service users to complete and return the surveys, and displaying recruitment flysheets in shared community spaces.

5.6.2 Join Dementia Research Database

This study used the online database 'Join Dementia Research'[2] (JDR) as a recruitment tool. This is an on-line self-registration service that enables volunteers with memory problems or dementia, carers of those with memory problems or dementia and healthy volunteers to register their interest in taking part in research. The purpose of JDR is to allow volunteers who are potentially eligible for studies to be identified, and contacted by researchers to further discuss potential inclusion.

It was not possible to screen potential participants based on whether they had a recent hospital admission. Therefore JDR returned several thousand potential participants. Using this platform it is not possible to send messages to multiple participants simultaneously. In order to maximize impact, a decision was made to focus on participants who self-identified as living with dementia or were designated as a proxy decision-maker for someone living with dementia- this helped reduce the number of emails sent to 'healthy' volunteers who were not eligible to participate.

[2] JDR is funded by the Department of Health working in partnership with the charities Alzheimer's Society and Alzheimer's Research UK, and is Health Research Authority (HRA) endorsed.

Using this strategy, approximately 1000 potential participants were e-mailed via the JDR platform. On request of the Department of Health-who track usage of JDR- a separate version of the survey was used to collect responses from JDR participants. This survey is identical in content and presentation to the other survey, but used a separate URL to allow the researcher to report back total number of responses collected via the platform. In total, 61 responses were received from participants who were identified via JDR. The option of receiving a paper survey was offered to every potential participant in the initial invitation e-mail, however, no one requested a paper copy be sent to them.

5.6.3 Professional networks

In addition to charitable partnerships- links to the survey were also disseminated using professional networks. These included the CHAIN network for Health Professionals with an interest in Dementia, the Emergency Medicine Improvement Program, and the Royal College of Emergency Medicine. As with the charitable partnerships, the initial approach to these professional networks was done via e-mail. Where colleagues at the University had existing relationships with members in these organisations, requests were sent via these contacts. The primary activity of professional networks was sharing the link to the online survey with their members via email update. Members of these professional networks were also asked to identify other potential organisations that had links to applicable service users.

As this research was funded by the Alzheimer's Society, they offered to promote the research via their research network volunteers. An e-mail was sent out to every member of the research network in the UK with a link to the survey. This reached a highly research active population and resulted in widespread response from a diverse geographic scope.

5.6.4 Social Media

The use of social media for networking and recruitment in health research is still relatively novel (Connor et al, 2013). The appeal of using social media for recruitment is linked to the ease of accessing a large and diverse

population and the fact many social media platforms are free for individual users to use. Social media was used widely in the recruitment of participants for this project; detail of how each individual platform was utilized is given below.

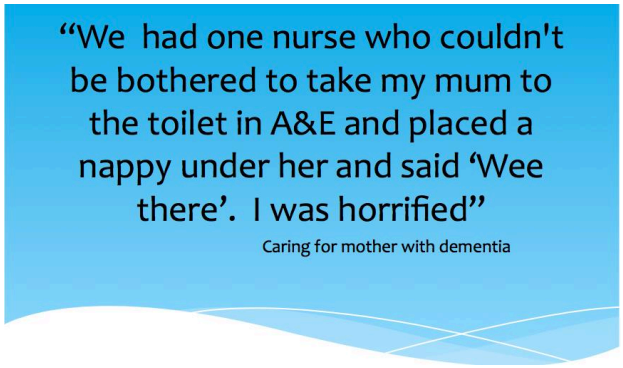
5.6.4.1 Twitter

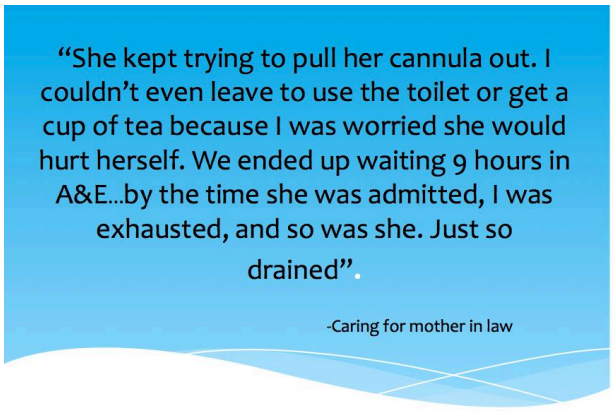
Promotion of the survey via twitter was a key strategy in recruitment. Twitter was used in two ways in this project; firstly it was used to reach potential respondents, and secondly it was used to identify potential recruitment and dissemination partners who were not identified in the pre-planning stages of the recruitment strategy.

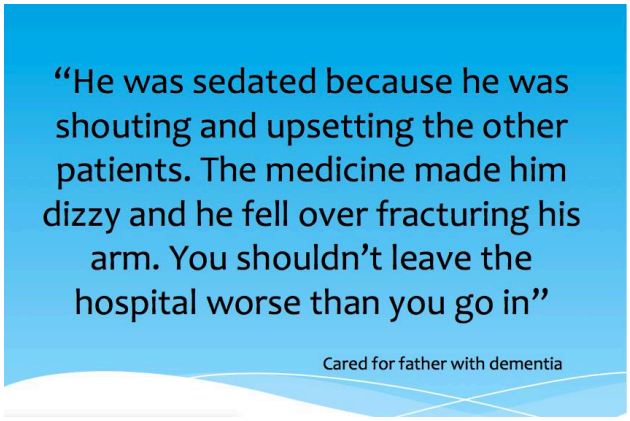
The challenge of reaching PWD in the community was identified early as a potential issue. There is a small, but active group of people living with dementia on Twitter, and it was determined that reaching out to these people to ask them to act as ambassadors and catalysts for dissemination would be an effective means of increasing the visibility of the survey and reach more people.

In addition to cascading the survey link via these key twitter contacts, tweets about the survey were shared up to four times daily from the primary twitter account of the researcher using dementia related hashtags including #Dementia #ADtalk #AlzCare #AlzSoc #carers #carersweek etc. In addition to hashtags, the tweets used pictures and use of evocative quotes to capture attention. Examples are given below.

Figure 15: Sample Tweets







Where it was appropriate to do so, contacts with large numbers of followers were tagged in these tweets to maximize the number of impressions. The initial recruitment tweet was pinned to the top of the account and over the course of three months had over 19,699 'impressions' including 109 re-tweets. Subsequent recruitment tweets had approximately 1000 impressions each, and averaged five re-tweets per post at the start of the recruitment campaign and 10 by the end of the campaign.

In addition to directly recruiting participants to the survey, twitter was also used to identify and connect with organisations that could assist with disseminating the survey. In addition to the initial partner organisations who were identified at the outset of the project, a further 25 partner organisations were identified and relationships developed through twitter engagement. These partner organisations participated in recruitment and dissemination activities as described above.

5.6.4.2 Talking Point

The Alzheimer's Society of the UK runs an online forum for people living with dementia and their carers to connect with each other. This forum has an area specifically for researchers to post and promote their research. A moderator controls access to this forum, and researchers must demonstrate they have NHSREC approval before they are given permission to post. Once this study was granted ethical approval, the researcher contacted the Talking Point manager to obtain permission to post a link to the information page in the research section of the forum.

This link was posted October 12st 2016, and followed up with 3 subsequent posts over the following 6 weeks to maintain visibility of the research and promote the survey. A notice of the expanded geographical scope of the survey was posted on April 12th, 2017.

5.6.5 Public engagement sessions

Occasionally the researcher was invited to speak publically about the ongoing research at public engagement events and conferences. At these events, if the audience was likely to include potential respondents, the researcher offered a brief introduction to the research and offered signposting to the online link to access the information sheet to enable people to determine if they would like to participate. Alternately, the researcher invited people to speak to them after the presentation to collect paper copies of the survey.

5.7 Returns

The surveys returned via post were collected monthly from the University mailroom and then entered manually into the online survey template for ease of analysis. Prior to being entered into the online template, surveys were stored in a locked filing cabinet. The data entry was completed by the researcher, and once entered the surveys were marked complete. Once the data entry was complete, the paper copies of the survey were destroyed.

5.8 Analysis

5.8.1 Quantitative

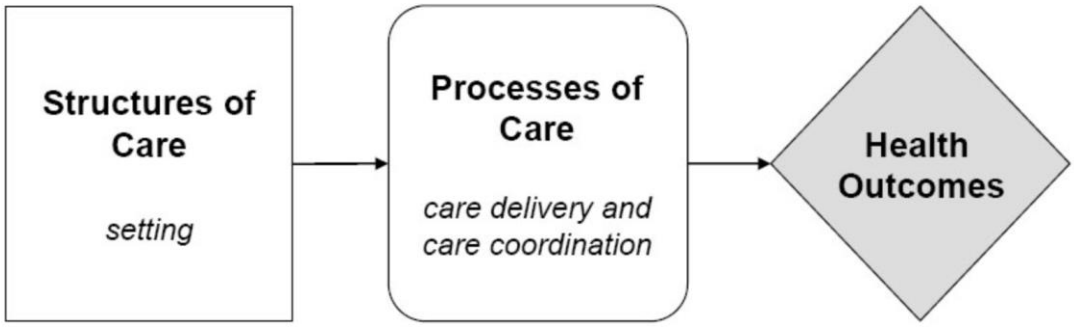
Data was migrated from the online database 'Bristol Online Survey' to SPSS statistical software (V24). The data was cleaned and coded as ordinal which is appropriate for Likert type data as it expresses a "greater than or less than relationship" without specifying this relationship as numerical or assuming equidistance between the items (Williams, 2003). The data was treated as non-parametric. Assessment of the data set made clear the low response rate by PWD (N=7) was insufficient to allow for meaningful statistical analysis separated by respondent type. Therefore, the two data sets from carer and PWD were merged prior to analysis. The first test was frequencies analysis to enable description of the overall data set. This was followed by inferential statistical tests.

The aim of the inferential testing was to determine which variables had a significant relationship on the respondents overall satisfaction with their care. Additionally, the analysis aimed to determine which variables are associated with provision of care that is perceived to be "dementia friendly". For this research the null hypothesis was that there is no association between the two variables, the hypothesis being that there is an association. To determine the relationship between variables, Pearson's Chi squared tests of independence was used to determine if there was a significant association between the two variables (Pallant, 2016). Spearman's correlation coefficient was then used to summarize the magnitude and directionality of the relationship between the two variables. The Spearman's correlation coefficient creates scores between -1 and 1, where -1 indicates a perfectly negative and +1 correlates to perfectly positive correlations. A score of 0 indicates no correlation, less than 0.5 (or 0-.5) is considered a weak correlation, and anything greater than 0.5 (or -0.5) a strong correlation (Pallant, 2016) .

5.8.2 Qualitative

Free text responses were analysed using thematic analysis. Thematic analysis enables the highlighting of reoccurring themes in a data set, and to illustrate the most 'salient constellations of meanings' in the phenomenon under study (Joffe, 2012). The first round of coding was done using three a priori codes- structures, processes, and outcomes- these codes are taken from the SPO model (Donabedian, 2003).

Figure 16: Donabedian Model



From McDonald, **Sundaram**, & **Bravata**, **2007**[3]

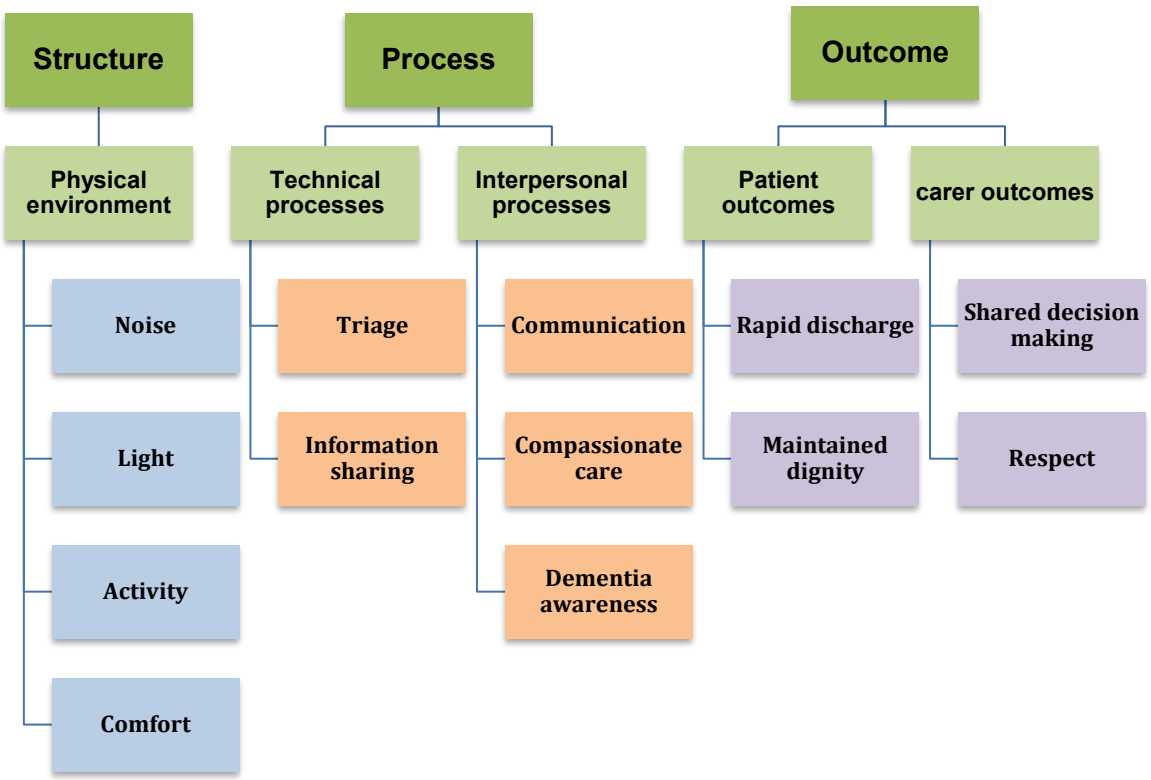
Structures are defined as "the physical and organizational aspects of care settings" (McDonald et al., 2007). This includes any fixed input into care that impact the context of care delivery including facilities, equipment, personnel, and organisational policies (Donabedian, 2003). Processes are defined as the actions that make up 'healthcare' at the point of delivery. These can include diagnostic actions, treatments, and interactions. Donabedian splits processes into two further categories of "technical processes" i.e. how care is delivered and "interpersonal processes" i.e. the manner in which care is delivered (Donabedian, 2003). Processes are central to the Donabedian model as they are influenced by the structures of the organisation, and have an impact on outcomes. Finally, outcomes are defined as the effect of healthcare on a

[3] Reprinted with permission of the U.S. Agency for Healthcare Research and Quality.

given population including promotion of recovery, functional restoration of ability,

The free text coding happened in three rounds. In the first round, the free text responses were separated into the three a priori codes. Where relevant, the same free text response could be given multiple codings if they offered commentary on multiple aspects of care. The second round of coding searched for emergent codes within the three different categories. In this round of coding an additional 18 codes were identified as emerging from the data. The final round of coding applied the 21 predefined codes to the full data set to organise the data and create cohorts of data for analysis. The coding framework is demonstrated in figure 9 below.

Figure 17: Free text coding framework



To ensure the coding was accurate, a sample of 10% of the free-text responses was shared with a colleague (AR) at the University of Bradford. This colleague had previous knowledge of the a priori codes, but not of the emergent

codes that were identified in the researcher's initial rounds of coding. A dual review of their coding revealed a high degree of congruency between the two coders for the a priori codes (36 out of 40) and non-aligned codings were resolved by discussion. The second coder found less of the emergent codes that were identified by the researcher, but expressed the opinion that this was likely a reflection of the small sample size for double coding. When queried, AR expressed preliminary thoughts about potential additional emergent codes- which aligned with the emergent codes identified by the researcher. AR indicated they had not felt confident in labelling them as 'official codes' at the time due to the small sample. Upon discussion of the emergent codes that the researcher identified and informal review of an additional set of free text responses, AR proposed that the other emergent codes were appropriately derived from the data.

5.9 Ethical issues

5.9.1 Research without written consent

For the survey stage of this research participants were not required to submit a signed consent form as this could have compromised their anonymity. This decision is pursuant to guidelines from the British Psychological Society on internet mediated research which states that completion and submission of a questionnaire can be taken as implied consent to participate provided the participant has been given adequate information to make an informed decision in the covering letter/ information sheet (The British Psychological Society, 2013) The guidance further suggests that best practice when using implied consent, is to add an additional 'tick box' or equivalent for respondents to indicate they have read the information sheet and agree to participate.

Potential participants in this study were shown or given an information sheet, which clearly explains the aims of the project, what is involved in participation, the potential risks and benefits, and the way the data will be used. For participants completing the survey online, this appeared as an information page prior to accessing the survey questions. Participants were required to

select "I have read and understand the information sheet, and agree to participate in this research project" before they were able to proceed with the survey questions. Participants completing the survey in paper-based format were given the same information sheet as a covering letter with a tick box at the end where participants indicated, "I have read and understood this information sheet, and agree to participate in this research project".

5.9.2 Capacity assessments

Capacity assessment was a critical concern in this phase of the research as the format of an online or paper survey did not involve direct interaction between the respondents and the researcher who would typically be responsible for capacity assessment prior to administration of a research survey. One of the key principles of ethical research is that respondents have given full and informed consent to their participation in the research (World Medical Association, 1964; Department of Health, 2005b) Because it was not possible to assess for capacity, a decision had to be made about how to ensure the research was not going to include people who were unable to understand the implications of their participation. Based on previous research, and discussion with the expert panel who advised on the research, it was decided that if a person with dementia was interested in completing the survey, and was able to comprehend the directions given on the information sheet and then successfully complete the survey, they should be assumed to have had capacity to make the decision to participate. To maximize the likelihood that the individuals would understand the task that was being asked of them, a link to an information video (https://youtube/VqWxzWPWezM) was shared alongside the information sheet, offering multiple ways of engaging with the information. PWD were also offered the option of completing the survey with support from another person.

5.9.3 English language exclusion

Regrettably for this study, due to scope and funding, inability to

communicate in English was an exclusion criterion. Excluding people who do not speak English creates the risk that data is not representative and frequently excludes people who are underrepresented in research activities (HRA, 2005). As researchers, there is an ethical duty to balance the need to create opportunities to participate for those who are seldom heard to ensure the representativeness of the data with the feasibilities of completing a project on time and within budget. The decision to exclude participants who do not speak English is in line with Heath Research Authority (HRA) guidance on the issue which indicates that there are certain circumstances- such as a small project funded by a grant, run by a Chief Investigator who doesn't speak additional languages, where "*recruitment of participants may need to be limited to those understanding English*." (Health Research Authority, 2005)

It was determined that it would not be feasible to translate the survey into the multiple languages that would be needed to ensure equal opportunity for all those participants (of different ethnicities) who do not speak English. In addition to the significant cost and time commitment this would entail, it would not be feasible to replicate the process of co-design and development that was used to create the English version. In summary, the language and content of the survey was carefully considered during the development and testing phases, and failing to replicate this review process with translated surveys would introduce the risk of ambiguous language or unclear translations.

Additionally, including people who do not speak English introduces the risk of confounding data. Dementia can impact both receptive and expressive communication, and a language barrier can have a similar impact on ability to communicate. Inability to communicate in English while accessing medical services and requiring the services of a translator-either family member or professional- adds an additional dynamic to the communication process. It would be difficult, if not impossible, to adequately control for the impact that an additional party (i.e. a translator) would have on the communication dynamic and a person's experience of hospital. Attempting to study multiple communication barriers in the same study could make it unclear if the person's

experience was related to their dementia, their language barrier, or a combination of both

.

Findings: Phase One

6.1 Introduction and purpose

This chapter reports results from phase one of this research, which consisted of a purpose built, co-designed survey. The aim was to gain a deeper understanding of the experiences of people living with dementia and the carers who support them when they attend an ED. In total, 409 responses[4] were received as part of this research, however six responses were discarded as they were from people who were located outside the geographical area indicated in the ethics application (Scotland (3) Wales (2) and the USA (1)). A total of 43 surveys were returned on paper, and the rest submitted online. No item received less than 395 responses.

Firstly, the survey findings are subjected to a descriptive analysis; this is followed by a statistical analysis, exploring the relationships between key items. The final section reports on the free text portion of the survey using Donabedian's SPO model as an analytic framework. The surveys can be found in Appendices six and seven)

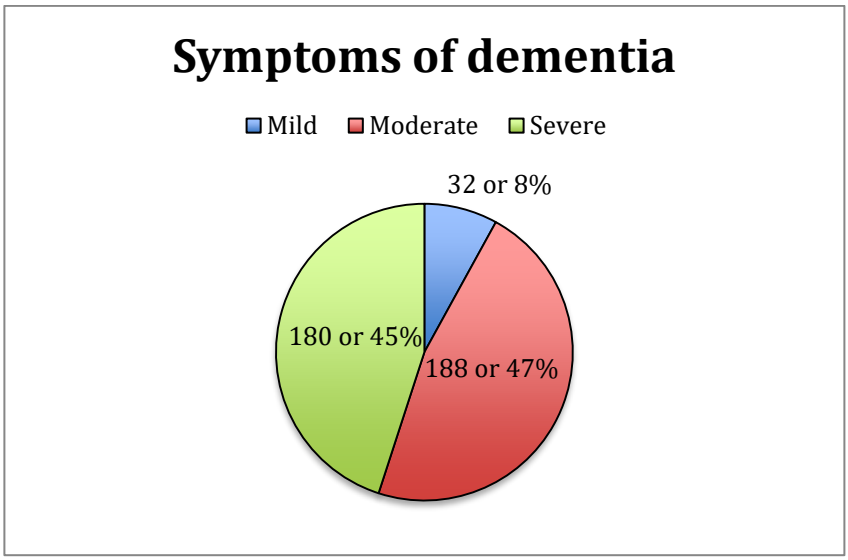
6.2 Descriptive analysis

6.2.1 Demographic/biographic details of respondents

Seven (2%) of the survey responses were from people living with dementia and the remaining 395 (98%) were completed by people who identified themselves as either currently, or formerly, caring for a PWD. Thirty-Nine (10%) respondents who identified themselves as a current or former carer indicated that they completed the survey together with the PWD. When asked how they would describe the dementia symptoms at the time of the admission 32 (8%) of respondents indicated they were 'mild', 188 (47%) indicated they were moderate, and 180 (45%) indicated they were severe.

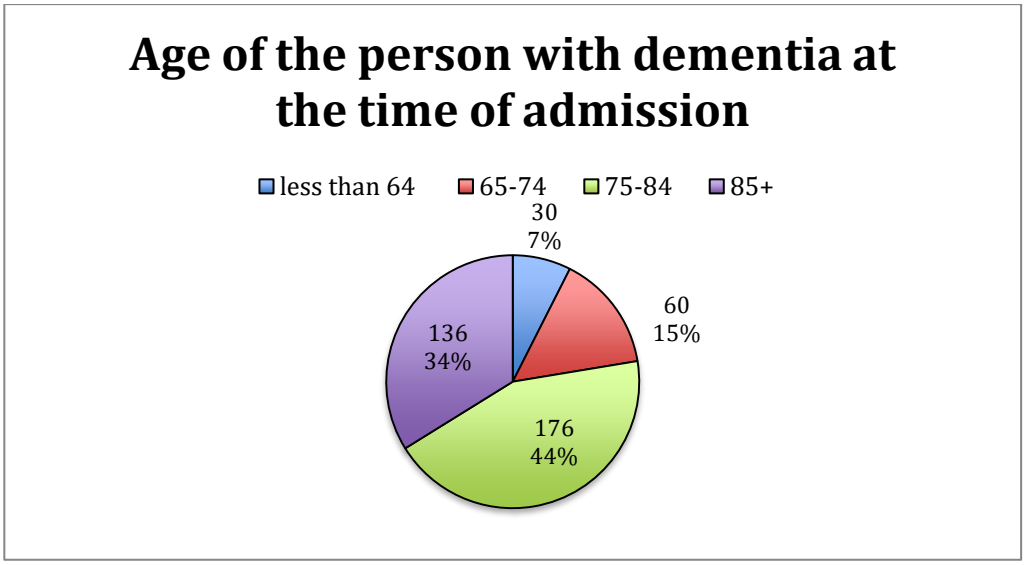
[4] See page 91 for formula used to calculate sample size

Figure 18: Symptoms of Dementia at time of admission



The majority of participants in the survey were reporting their experiences of attending an ED with someone over the age of 75. In total, 312 (78%) responses were for patients who were over 75 at the time of admission; this is split into 176 (44%) aged 75-84, and 136 (34%) for those 85 and older. The figure of 22% of admissions under 75 is significantly higher than the overall proportion of PWD under 75 in the UK.

Figure 19: Age of the person with dementia at the time of admission



The most frequently cited reason for attending the ED was “acute illness” accounting for 172 (43%) of attendances. This is followed by minor accidents and major accidents, which each accounted for 76 (19%) admissions; 42 (11%) of attendances were related to mental health, and 34 (8%) were related to a life threatening injury or illness.

Figure 20: Main reason for attending the hospital

Minor accident: *sprains, cuts needing stiches, ect*	76	19%
Major accident: *broken bones, multiple injuries, blood loss, head injury ect*	76	19%
Acute illness : *existing medical condition got worse or new condition requiring urgent attention*	172	43%
Life threatening injury or illness: *stroke, heart attack, multiple injuries, serious blood loss*	34	8%
Mental Health: *significant changes in behaviour, memory, or increases in confusion*	42	11%

In a majority of cases, the decision to attend the ED was made by healthcare professionals in the community, such as general practitioners, district nurses, or paramedics. Ambulance crews or paramedics made the decision to attend in 178 cases (45%) and other health care professionals in the community made the decision in 106 cases (26%). The “primary carer of the person with dementia” made the decision to attend in 86 cases (21%) and “another family member who provides support” accounted for a further 11 cases (3%). In 12 cases (3%) the attendance was on the advice of the NHS 111 service. The PWD themselves made the decision to attend hospital in 7 cases (2%).

A total of 332 (84%) survey respondents indicated that they arrived at the ED via ambulance with paramedics. Of the respondents who indicated they arrived via ambulance 59 (15%) indicated that the ambulance crew used lights and sirens during conveyance, and 273 (69%) indicated no lights or sirens were used. The remaining 65 (16%) respondents indicated that they arrived at the hospital on their own, either in a personal vehicle or taxi.

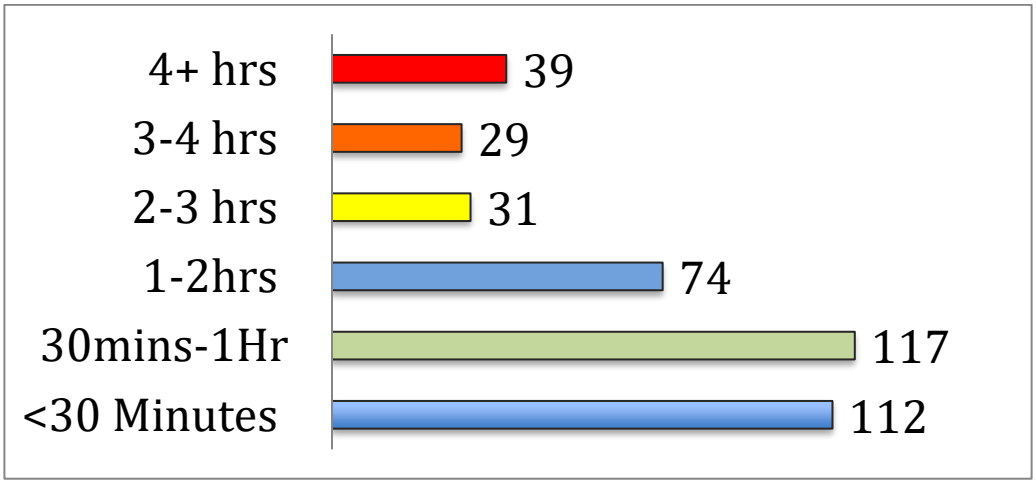
Slightly over half of the attendances were during the day, with 220 (56%) of respondents indicating they arrived between 8am and 5pm. A further 104 (27%) indicated they arrived in the 'evening' between 5pm and 10pm, and 65 (17%) said they arrived 'overnight' between 10pm and 8am. In total 272 (68%) respondents indicated that after the visit to ED, the PWD was admitted to the hospital, whereas 130 (32%) said they received treatment and were discharged from the ED.

6.2.2 Admission

This section of the survey explored respondents' experiences of their initial reception and assessment in the ED, including the triage process and physical environment. All but one item in this section was presented on a Likert scale (See Pg. 85 for an example).

The first item inquired how long the person with dementia waited to see a doctor or nurse; 56% (N=229) of the respondents saw a doctor or a nurse for an initial assessment within one hour of arrival

Figure 21: How long did you wait to see a doctor or nurse?



The remaining questions in this section queried the experiences of patients and carers in the waiting and assessment period.

Figure 22: Survey results- Admissions section

	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree
There was a quieter space available for me to use in the waiting area	17 *(4%)*	48 *(12%)*	98 *(24%)*	107 *(27%)*	132 *(33%)*
The staff member who assessed me took time to ask about any recent changes in behaviour and / or memory	24 (6%)	107 (27%)	73 (18%)	103 (26%)	93 (23%)
I (or the person with dementia) was encouraged and supported to share relevant medical history	44 (11%)	186 (47%)	53 (13%)	71 (18%)	46 (11%)
I (or the person with dementia) became more anxious / confused while I waited to be seen	123 (31%)	141 (35%)	77 (19%)	48 (12%)	13 (3%)

Notably in these responses, only 65 (16%) agreed or strongly agreed that there was a quiet or quieter space available. Given the importance given to recognition and identification of dementia in acute care, it is somewhat surprising to find that only 131 (33%) agreed or strongly agreed that the staff member who assessed them took time to ask about any recent changes in behaviour or memory- even more pertinent is recognition that within that group, only 24 (6%) strongly agreed.

6.2.3 Treatment

The next section of the survey queried the respondent's experiences during the time spent in the ED before the patient was diagnosed or treated. The focus of these questions is on the physical environment of the ED and the patient's emotional state. All the questions in this section were presented on as above, on a five point Likert scale. Of the seven responses received from PWD,

three indicated that when they attended they did not have a carer or supporter with them during their time in ED- therefore the overall sample for these questions is 400 responses rather than 403 as per the rest of the data set.

Figure 23: Survey Results- Treatment section

	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree
There was a quieter space available while waiting for treatment or waiting to be admitted to a ward.	19 (5%)	91 (23%)	77 (19%)	95 (24%)	115 (29%)
The noise level in the A&E or Minor Injuries Unit made the person with dementia more anxious / confused	84 (21%)	143 (36%)	82 (20%)	77 (19%)	16 (4%)
The physical space of the A&E or Minor Injuries Unit was safe and comfortable for someone with dementia	10 (3%)	89 (22%)	86 (21%)	125 (31%)	92 (23%)
I was able to see signs directing me to facilities such as reception and toilets.	19 (5%)	167 (42%)	69 (17%)	113 (28%)	34 (8%)
The carer was encouraged to stay with the patient in A&E or the Minor Injuries Unit the whole time I was there. (No carer present =N3)	92 (23%)	143 (36%)	72 (18%)	68 (17%)	24 (6%)
The carer was encouraged to accompany the patient during moves (No carer present= N3)	64 (16%)	128 (33%)	72 (18%)	86 (22%)	45 (11%)
I/the person with dementia became more anxious / confused the longer I/they spent in A&E	138 (34%)	131 (33%)	63 (16%)	57 (14%)	13 (3%)

The query about the perceived association between increased anxiety or confusion and length of stay in the department is repeated in the admissions and treatment section. Comparing the results between the two items indicates a

slight increase in the number of people strongly agreeing from 123 (31%) in the treatment to 138 (34%). There was a small fall in the number of those 'agreeing' from 141 (35%) to 131 (33%). There was a similar sized increase in the number of people who disagreed from 48 (12%) to 57 (14%). The number of those who strongly disagreed remained constant at 13 (3%).

6.2.4 Staffing

The items here asked respondents to reflect on the interactions with staff in the ED while the PWD was being treated. The focus of these items is the number and skill of the staff and continuity or accessibility of care in ED. All the items in this section were presented on a Likert scale as above.

Figure 24: Survey results- Staffing

	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree
I felt there were enough staff to provide good care for all the patients who were there.	5 *(1%)*	72 *(18%)*	50 *(13%)*	150 *(37%)*	124 *(31%)*
The medical staff who were providing care for me seemed to have a basic awareness of Dementia	19 *(5%)*	161 *(40%)*	77 *(19%)*	83 *(21%)*	60 *(15%)*
The medical staff provided dementia friendly care for me	18 *(4%)*	91 *(23%)*	96 *(24%)*	106 *(26%)*	91 *(23%)*
The non-medical staff who interacted with me seemed to have a basic awareness of Dementia	7 *(1%)*	92 *(23%)*	135 *(34%)*	107 *(27%)*	59 *(15%)*
The non-medical staff provided dementia friendly care for me	9 *(2%)*	78 *(20%)*	149 *(37%)*	105 *(26%)*	59 *(15%)*

The same doctors and nurses provided care for me during my time in A&E or the Minor Injuries Unit	14 *(3%)*	119 *(30%)*	55 *(14%)*	149 *(37%)*	62 *(16%)*
I was comfortable with the staff who provided personal care	20 *(5%)*	155 *(39%)*	109 *(27%)*	72 *(18%)*	46 *(11%)*
I was able to raise the attention of staff to get help when needed.	16 *(4%)*	151 *(37%)*	76 *(19%)*	108 *(27%)*	51 *(13%)*

6.2.5 Communication

The final section of the survey queried the quality of, and approaches to, communication between healthcare staff and patients or carers. The aim of this section was to explore how people perceive communication in the ED setting, and to enable analysis of how various aspects of communication impacted overall satisfaction with care.

Figure 25: Communication

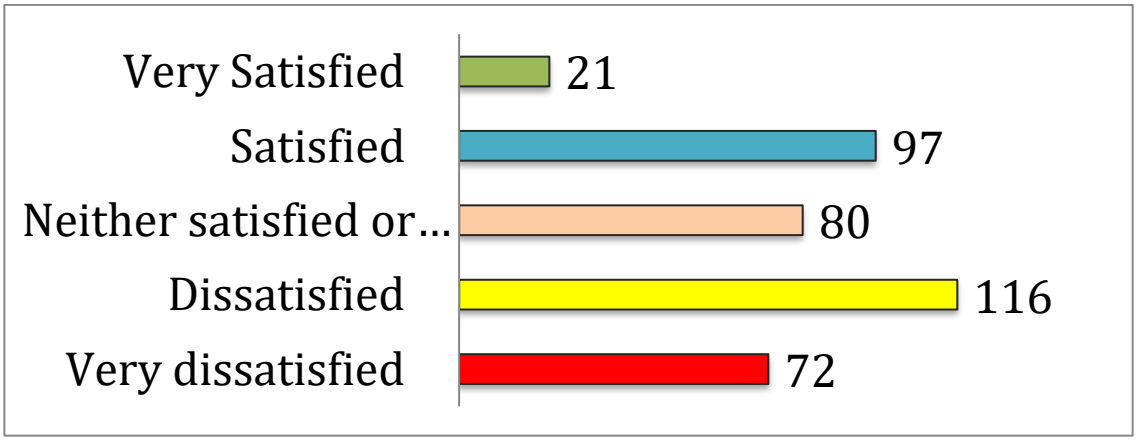
	Strongly agree	**Agree**	**Neither agree or disagree**	**Disagree**	**Strongly disagree**
The staff who provided care to me seemed to understand that I may have problems communicating	35 (9%)	168 (42%)	53 (13%)	97 (24%)	49 (12%)
The staff who provided care to me used language that was easy to understand	25 (6%)	175 (44%)	72 (18%)	88 (22%)	40 (10%)
The staff made an effort to speak to the person with Dementia	33 (8%)	219 (55%)	62 (15%)	57 (14%)	31 (8%)
The staff preferred to talk to the carer or supporter	66 (17%)	141 (35%)	98 (25%)	80 (20%)	13 (3%)
I felt respected and that my contribution was valued when I communicated with staff	48 (12%)	188 (47%)	67 (17%)	63 (16%)	34 (8%)

I was encouraged to participate in the care of the person with dementia in a way I was comfortable with	45 (11%)	162 (40%)	98 (25%)	63 (16%)	33 (8%)
I felt I was asked to take on more caring responsibility than I was comfortable with	41 (11%)	69 (18%)	95 (24%)	149 (38%)	36 (9%)
Information about the diagnosis and care of the person I supported was communicated promptly	32 (8%)	133 (33%)	70 (17%)	103 (26%)	64 (16%)

6.3 Conclusions

The final item of the survey asked respondents to share how satisfied they were with the dementia care they received in ED. Overall, just 21 (6%) indicated they were very satisfied and a further 98 (25%) indicated they were satisfied. In comparison, 75 (19%) indicated they were very dissatisfied, and 117 (29%) said they were dissatisfied. The remaining 82 (21%) indicated they were neither satisfied nor dissatisfied. While these results suggest there is some satisfaction, there is clearly room for improvement and a great deal of variation between services.

Figure 26: Overall, how satisfied were you with the dementia care in ED



6.4 Statistical analysis

As noted in the preceding methods chapter, the data was analysed using Chi squared tests of (two way) association and for each relationship the

Spearman correlation coefficient was calculated. Both tests can be used with ordinal, non-parametric data such as these; the assumptions for use of the Chi Square test were met including that 80% of more of the cell counts were greater than 5.

These tests were used to determine which variables had a significant association with 1) overall satisfaction with care in ED and 2) perception of dementia friendly care. Additionally, the Spearman's correlation co-efficient has been used to rank the variables in descending order of relative association to determine which features of care are most strongly associated with overall satisfaction and perceptions of dementia friendly care.

A total of 29 variables had a statistically significant relationship with "overall satisfaction". Of these 29 variables, 16 of them had a Spearman's correlation co-efficient of over .5, which indicates a strong correlation, 10 had a moderate association (R_s >.3 and <.5) cases including both positive and negative associations, and the remaining three had weak (R_s <.3) associations (Pallant, 2016).

Figure Nineteen (Pg. 117) offers a summary of these results in table format.

The variables which have a significant association and a strong correlation (presented in descending order) include;

- The medical staff provided dementia friendly care for the person with dementia
- The medical staff who were providing care for me seemed to have a basic awareness of dementia
- The staff who provided care to the person with dementia seemed to understand that they may have trouble communicating
- The staff who provided care used language that was easy to understand
- The non-medical staff provided dementia friendly care to me
- The non-medical staff provided dementia friendly care for the person with dementia
- I felt respected and that my contribution was valued when I communicated with staff
- I was encouraged to participate in the care of the person with dementia in a way I was comfortable

- I was able to raise the attention of staff to get help when needed
- I was comfortable with the staff who provided personal care
- The staff member who assessed the person with dementia took time to ask about any recent changes in behaviour and/or memory
- Information about the diagnosis and care of the person with dementia was communicated promptly
- I felt there were enough staff to provide good care for all the patients who were there
- The same doctors and nurses provided care to the person with dementia during their time in A&E
- The physical space of the A&E was safe and comfortable for the person with dementia, and
- The staff made an effort to speak to the person with dementia"

The variables that have a significant association, and have a moderate Spearman's correlation- presented in descending order- include

- The person with dementia was encouraged and supported to share relevant medical history
- There was a quieter area available in the waiting area
- There was a quieter area available while waiting for treatment or waiting to be admitted to a ward
- The carer was encouraged to stay with the person with dementia for the duration of the patients stay in A&E
- The carer was encouraged to stay with the person with dementia during moves

One variable " *I was able to see signs directing me to facilities such as reception and toilets"* was statistically significant, but had a weak correlation.

Some variables demonstrated a negative correlation with satisfaction; however, none of these correlations reaches the -0.5 threshold. The variables, which demonstrated moderate negative correlation, include

- I felt I was asked to take on more caring responsibility than I was comfortable with
- How long where you waiting to see a doctor or nurse for the first time
- The person with dementia became more anxious or confused the longer they spent in A&E"
- The noise level in A&E made the person with dementia more anxious or confused" and,

- The person with dementia became more anxious or confused while they waited to be seen

Two variables were statistically significant, but demonstrated only weak negative correlation. These are " *I felt the staff preferred to talk to the carer rather than the person with dementia"* and "*How long ago was the admission*" which demonstrated a significant, but small inverse correlation between the length of time since the admission and overall satisfaction.

No significant associations were found between satisfaction and:

- Whether a person is a carer or person with dementia,
- The age of the person with dementia at the time of admission
- The main reason for attending hospital
- Who made the decision to attend hospital
- The means of arrival at hospital
- The time of admission
- Whether the patient was discharged or admitted to the hospital,
- The severity of dementia symptoms at the time of admission.

A further aim of this research was to identify which variables are associated with a patient or carers perception that they have received "dementia friendly care". As with satisfaction, the association between 'dementia friendly care" and the other items was measured using chi squared test of independence, and the magnitude and direction of these associations was measured using Spearman's correlation co-efficient. Analysis demonstrated a statistically significant association between "dementia friendly care' and 26 other variables. The association can be considered strong (R_s >0.5) in ten of these associations, moderate (R_s >.3 and <.5) in 13 cases including both positive and negative associations, and weak (R_s <.3) for the remaining three associations.

Figure twenty (Pg.119) offers a summary of these results in table format.

Strong correlation was found between provision of 'dementia friendly care' and;

- The medical staff providing care to me had a basic awareness of dementia
- The staff who provided care seemed to understand the person with dementia may have problems communicating
- The staff who provided care to me used language that was easy to understand
- I felt respected and that my contribution was valued when I communicated with staff
- I was encouraged to participate in the care of the person with dementia in a way I was comfortable with
- I was able to raise the attention of staff to get help when needed
- I was comfortable with the staff who provided personal care
- The staff who assessed the person with dementia took time to ask about any recent changes in behaviour or memory
- The same doctors or nurses provided care for the person with dementia during their time in A&E, and
- Information about diagnosis and care of the person with dementia was communicated promptly.

Moderate positive correlation was found between 'dementia friendly care' and,

- I felt there was enough staff to provide good care for all of the patients that were there
- The staff made an effort to speak to the person with dementia
- The physical space of A&E was safe and comfortable for someone with dementia
- There was a quieter space available for the person with dementia to use in the waiting area
- There was a quieter space available for the person with dementia to use while they waited for treatment or waiting to move to a ward
- The person with dementia was supported and encouraged to share relevant medical history
- The carer was encouraged to stay with the person with dementia during moves
- The carer was encouraged to stay with the person with dementia the whole time they were in A&E.

There was a moderate, negative relationship between 'dementia friendly care' and,

- I felt I was asked to take on more caring responsibility than the I was comfortable with
- The person with dementia became more anxious or confused the longer they spent in A&E
- The noise level of A&E made the person with dementia more anxious or confused

- How long were you waiting to see a doctor or nurse for the first time, and
- The person with dementia became more anxious or confused while they [were in the waiting area]

Weak, but still statistically significant association was found between dementia friendly care and

- I was able to see signs directing me to facilitates such as reception and toilets
- How would you describe the symptoms of dementia at the time of the A&E visit, and
- I felt the staff preferred to talk to the carer rather than the person with dementia.

This analysis also found significant inverse associations between the provision of a quieter space in the waiting area and the treatment area with self reported increases in anxiety or confusion. Indicating the provision of a quiet or quieter area is associated with reduced risk of increasing anxiety or confusion.

Figure 27: Satisfaction

Variable	Chi squared	DF	2 tailed sig	Phi	Spearman
The medical staff provided dementia friendly care for me	405.297	16	.000	1.009	.764
The medical staff who were providing care for me seemed to have a basic awareness of Dementia	304.439	16	.000	.877	.660
The staff who provided care to me seemed to understand that I may have problems communicating	247.037	16	.000	.778	.647
The staff who provided care to me used language that was easy to understand	270.584	16	.000	.827	.633
The non-medical staff provided dementia friendly care for me	248.503	16	.000	.792	.622
The non-medical staff who interacted with me seemed to have a basic awareness of Dementia	238.566	16	.000	.776	.619
I felt respected and that my contribution was valued when I communicated with staff	241.541	20	.000	.781	.606
I was encouraged to participate in the care of the person with dementia in a way I was comfortable with	242.063	16	.000	.781	.605
I was able to raise the attention of staff to get help when needed.	239.209	16	.000	.775	.605
I was comfortable with the staff who provided personal care	247.863	16	.000	.789	.598
The staff member who assessed me took time to ask about any recent changes in behaviour and / or memory	187.450	16	.000	.688	.556
Information about the diagnosis and care of the person I supported was communicated promptly	166.338	16	.000	.646	.549
I felt there were enough staff to provide good care for all the patients who were there.	147.992	16	.000	.611	.521
The same doctors and nurses provided care for me during my time in A&E or the Minor Injuries Unit	223.640	16	.000	.751	.518
The physical space of the A&E or Minor Injuries Unit was safe and comfortable for someone with dementia	132.695	16	.000	.577	.518

The staff made an effort to speak to the person with Dementia	188.102	16	.000	.687	.517
The person with dementia was encouraged and supported to share relevant medical history	160.484	16	.000	.637	.477
There was a quieter space available in the waiting area	115.657	16	.000	.539	.474
There was a quieter space available while waiting for treatment or waiting to be admitted to a ward.	124.218	16	.000	.562	.443
The carer was encouraged to stay with the patient in A&E or the Minor Injuries Unit the whole time I was there.	125.073	20	.000	.561	.425
The carer was encouraged to accompany the patient during moves	118.546	20	.000	.549	.410
I was able to see signs directing me to facilities such as reception and toilets.	56.712	16	.000	.377	.217
How long ago was the admission	17.761	8	.023	.212	-.183
I felt the staff preferred to talk to the carer rather than the person with dementia	70.435	16	.000	.421	-.275
The person with dementia became more anxious / confused while they waited to be seen	65.261	16	.000	.405	-.350
The noise level in the A&E or Minor Injuries Unit made the person with dementia more anxious / confused	101.801	16	.000	.506	-.435
I/the person with dementia became more anxious / confused the longer I/they spent in A&E	124.193	16	.000	.559	-.449
How long were you waiting to see a doctor or nurse for the first time?	106.428	20	.000	.517	-.462
I felt I was asked to take on more caring responsibility than I was comfortable with	142.159	16	.000	.608	-.481

Figure 28: Dementia Friendly Care

Variable	Chi squared	DF	Sig	Phi	Spearman
The medical staff who were providing care for me seemed to have a basic awareness of Dementia	587.850	16	.000	1.212	.752
The staff who provided care to me seemed to understand that I may have problems communicating	286.612	16	.000	.844	.678
The staff who provided care to me used language that was easy to understand	266.335	16	.000	.816	.620
I felt respected and that my contribution was valued when I communicated with staff	213.658	20	.000	.731	.612
I was encouraged to participate in the care of the person with dementia in a way I was comfortable with	215.092	16	.000	.732	.579
I was able to raise the attention of staff to get help when needed.	209.630	16	.000	.722	.557
I was comfortable with the staff who provided personal care	200.945	16	.000	.707	.555
The staff member who assessed me took time to ask about any recent changes in behaviour and / or memory	165.374	16	.000	.643	.525
The same doctors and nurses provided care for me during my time in A&E or the Minor Injuries Unit	206.946	16	.000	.720	.509
Information about the diagnosis and care of the person I supported was communicated promptly	159.233	16	.000	.629	.503
I felt there were enough staff to provide good care for all the patients who were there.	140.179	16	.000	.591	.495
The staff made an effort to speak to the person with Dementia	190.397	16	.000	.688	.494
The physical space of the A&E or Minor Injuries Unit was safe and comfortable for someone with dementia	120.603	16	.000	.548	.456
There was a quieter space available in the waiting area	96.876	16	.000	.491	.412
There was a quieter space available while waiting for treatment or waiting to be admitted to a ward.	106.464	16	.000	.518	.406
The person with dementia was encouraged and supported to	104.853	16	.000	.512	.399

share relevant medical history					
The carer was encouraged to accompany the patient during moves	144.268	20	.000	.602	.385
The carer was encouraged to stay with the patient in A&E or the Minor Injuries Unit the whole time I was there.	113.310	20	.000	.531	.351
I was able to see signs directing me to facilities such as reception and toilets.	53.356	16	.000	.364	.159
How would you describe the symptoms of dementia at the time of the A&E visit?	24.205	12	.019	.246	-.050
I felt the staff preferred to talk to the carer rather than the person with dementia	54.493	20	.000	.369	-.194
the person with dementia became more anxious / confused while they waited to be seen	64.402	16	.000	.401	-.300
How long were you waiting to see a doctor or nurse for the first time?	71.780	20	.000	.423	-.353
The noise level in the A&E or Minor Injuries Unit made the person with dementia more anxious / confused	101.793	16	.000	.503	-.365
I/the person with dementia became more anxious / confused the longer I/they spent in A&E	109.100	16	.000	.521	-.402
I felt I was asked to take on more caring responsibility than I was comfortable with	95.804	16	.000	.496	-.417

6.5 Free text responses

The final item in the survey gave respondents a short space to provide feedback on their experiences in free text. In total 310 (79%) respondents shared reflections or comments on their experiences. As noted in the methods chapter, these responses are presented using Donabedian's SPO model as a framework.

6.5.1 Structures

To reiterate, structures are defined as "the physical and organizational aspects of care settings" (McDonald et al., 2007,pg 113) which includes any fixed input into care that impact the context of care delivery including facilities, equipment, personnel, and organisational policies (Donabedian, 2003). The majority of responses that discussed the structures of care highlighted challenges within the physical environment of ED. These included- but were not limited to- excessive noise, constant bright lights, continual activity, and poor access to comforts such as food, drinks, or softer furnishings or seating to rest.

Noise was a key challenge for many respondents, stating "*noises and lighting are an issue- my mother was disturbed by these (C303)*" and "*It's a confusing time for someone with dementia-there is too much noise*"(C3). Several people suggested that a quiet or quieter area-potentially separate from the main ED area- would be beneficial, stating: "*a quiet area for him to wait would have been very beneficial*"(C22) and "*It would help to have a quiet dementia friendly space within A&E*"(C38).

Similarly, some respondents, especially those who attended ED at night, highlighted the lighting as an issue. Respondents felt that it was disorientating for a patient to have bright lights on when they would typically be asleep. One respondent who had enjoyed a good experience attributed this in part to the ability to turn the lights out in the cubical. S/he stated: "*We turned lights off and Mum slept in between being seen by doctors*" (C206) which reduced the strain on both the carer and the patient.

Another major issue with the environment was the constant activity in ED that can be distressing and disorientating for some people with dementia. This was particularly notable when patients spent extended time in corridors or other high traffic areas in the ED. Carers shared experiences like: "*my mother was in the entrance with her head in front of a banging swing door for 3 or 4 hours*" (C18) which was felt to increase her agitation and make the experience more stressful. As an alternative, the respondents would prefer "*a quieter room, with a door, to reduce the over stimulation effect of a busy ED*" (C78).

Lastly, a large number of respondents (N=140 or 35%) wrote that access to items that provided comfort was limited. In particular, poor access to food and drinks in ED was a major issue. Many felt that having to leave the ED area to get a hot drink or food was a stressor, as they had to leave their relative unattended in ED. They commented: *"I couldn't leave him alone to go to the toilet or get food or drinks*" (C201) and "*There were no drinking water facilities-you had to exit A&E and go to main hospital*" (C26). Carers also commented that patients were often left on trolleys for extended periods, increasing the distress the patient experienced. They commented "*My husband was kept on a trolley for hours and he became extremely agitated"(C126)* and *"he was on a hospital trolley for nearly 9 hours before being transferred to a bed-he is 93 years old and became increasingly uncomfortable and agitated*" (C163). As an alternative, carers and patients wanted options for comfortable seating- perhaps a "*lounge type arrangement (C34)*' where "*patients can get up and walk around safely" (C240).*

In conclusion, the respondents identified several of the key environmental concerns that have been highlighted in previous research as challenging for PWD. Ideally, a dementia friendly ED would have a separate, quiet or quieter space available, with lights which can be controlled locally and easy access to comfort including soft furnishings, food and drink.

6.5.2 Processes

Processes are the actions that make up healthcare at the point of delivery. Donabedian splits processes into two further categories of 'technical

processes' i.e. what care is delivered and 'interpersonal processes' i.e. the manner in which care is delivered (Donabedian, 2003). The coding framework mirrors these initial codes. The key issues highlighted under technical processes are deficiencies in the triaging process that fail to take a patient's dementia into account and poorly designed processes to transfer information. Key issues in interpersonal processes included inappropriate means of communicating with the patient, lack of compassionate care, and poor awareness of dementia.

Firstly, carers highlighted the challenges that arose during the initial triage and screening. Very few felt the holistic needs of the PWD were taken into account during the initial consultation. They fed back comments like: "*Assessment of condition did not take into account the dementia*" and "*Dementia affects everything, not just medical problems- hospitals need to look at a patients holistically*" (C85). One carer shared an example of their experience saying "*When we first booked in at reception I passed on that my husband had Alzheimer's and to save embarrassing him would she please pass this information on. She not only failed to do this but made me feel that I was only saying this to queue jump*" (C69). Carers also commented that they would prefer if PWD were given priority in triage as the environment of ED has such a negative impact on the person.

Furthermore, carers commented that the processes used to transfer information were not always effective in ED- especially when they rely on the patient being able to give accurate information or physical transfer of notes. They shared experiences, saying things like: "*the patients notes were sent from care home to paramedic to A&E, but then were lost and when I arrived they had no history*" (C168) and "*if I hadn't have been there I doubt the medical staff would have got the correct information from my father and they would have believed everything he told them*" (C50).

Additionally, carers expressed concern that when information is not shared effectively it puts patients at risk. Several shared examples when the patient was discharged late at night, to an incorrect address, without keys or someone there to support them. The carers also expressed concerns about an

inability to get accurate information from the PWD if healthcare staff give follow up care instructions to the patient, saying, "*the patient was given verbal information they were expected to retain or pass on to family*" (C85).

In interpersonal processes- that relate more directly to the experience of care at the bedside- the core issues raised by respondents tended to focus on the approach to communication and staff awareness of dementia. Carers felt staff would benefit from additional training in more effective ways of communicating with PWD including: "*giving the patient time to verbalise what they are trying to say and not rush them*" (P41) and allowing the carer to answer if the patient is overwhelmed or unable to articulate (C5, C64, C101, C135, C138, C245, C261, C311)

People shared their poor experiences of communication at the bedside, writing: " *they were not listening, talking over rather than talking to my husband- It added to the stress we were both feeling rather than assisting and reassuring us all would be okay*"(C170) and "*Staff should speak gently to the person with dementia, introducing themselves and explaining what they need to do and why, before they carry out a procedure" (C123).*

Overall, it was felt that there was a poor understanding of the realities of dementia amongst many staff. The respondents felt that while some staff had an understanding of the medical implications of dementia, this did not translate into dementia friendly approaches to care. They fed back comments such as: "*staff training in dementia is needed-more support and understanding needed and a more sensitive and friendly approach*"(C131) and "*all staff must be dementia trained and value dignity and respect to people with dementia*"(C38). Many felt that poor understanding of dementia resulted in care that was not dignified or compassionate.

6.5.3 Outcomes

Several respondents took the free-text response option to share their feelings on what constituted a 'good' outcome following a visit to ED. These can be split onto patient outcomes and carer outcomes. According to the

respondents, the two key positive outcomes for patients are rapid discharge or transmission through the ED and maintenance of dignity in the ED. For carers, the important outcomes are feeling there has been shared decision making and being treated with respect.

For patients, the best outcome is to exit the ED environment as quickly as possible. For some this is facilitated through rapid assessment and discharge to the community, and for others it depended on expedient assessment and transfer to a ward. Several people highlighted the importance of minimizing time spent in the ED: "*fast track through to ward if needed*"(C225) and "*dementia patients should be fast tracked through A&E*" (P25). They also commented on the importance of ensuring PWD get home rapidly after being assessed as medically fit for discharge, writing: "*fast track transport to get the patient home when discharged*" (C214).

The other key outcome highlighted as essential for the patient with dementia is the maintenance of dignity throughout the persons stay in ED. Comments such as: "*show compassion and treat the person with dignity"(C236)* and "*talk to them as human beings with feelings*"(C200) highlight the importance of person centered care in the ED. Several respondents shared experiences of being left to care for relatives who had been incontinent which they reported had a profoundly distressing impact on the patient and increased carer's stress.

In contrast, several respondents who reported they had good experiences highlighted the preservation of dignity. One stated: "[the hospital] *and its' staff were a breath of fresh air and should be held as an example of how Dementia patients should be cared for across all hospitals- ensuring they keep their dignity and feel safe in their surroundings*" (C93). This feedback enables the conclusion that maintenance of dignity is an important outcome for PWD in ED.

Finally, carers who responded to the survey felt there were certain outcomes relating to their experiences that are important indicators for 'good care'. The first was feeling they were involved in decision making and care planning for the PWD. A significant number of carers expressed frustration that

they were not involved in care planning or decision making while their relative was in ED. They said things like: "*Staff should speak to carers to ascertain usual routines*" (C92) and "*the staff should listen to the carer, my comments were ignored, in a 'we know better' attitude*"(C156). One respondent shared their experience of accompanying their father to the department. Despite calling ahead to say he was distressed and there was concern about a potentially fractured neck of femur, the patient was discharged without an x-ray for exhibiting 'combative' behaviour. This respondent felt if the staff had listened and allowed them to accompany the patient they could have avoided the negative experience (C304). Others shared stories of being sent away or not being allowed to accompany their relative for medical investigations and assessments. These experiences caused frustration for the carers and they felt these interactions had a negative impact on the patient's experience and safety while they were in the ED.

Closely linked to the idea of developing care partnerships is the importance of feeling respected as a carer. In fact, this was expressed so strongly, it appeared to be generalisable outcome measure for carers. This sentiment was expressed with statements like: "*as a carer, I must be listened to, and supported in A&E- I know my Mum better than anyone!*"(C38) and "*don't make the carer feel like a nuisance*" (C58).

Carers also expressed a desire that their needs as carers- for food, drink, a place to sit, and compassion- should be recognised and respected. They stated "*Eight hours in A&E with no food or drink offered to carer*"(C224) and" *worst seven hours I ever spent*"(C230). Several respondents shared experiences of being left to manage difficult behaviours from their relatives for hours at a time with no offer of assistance from staff, stating "*I know about health and safety concerns, but they just left me while I was getting hit by Dad*" (C406). Consequently many commented that the experience was made even more stressful and they were unable to meet their own personal needs. These experiences left the carers feeling abandoned, forgotten and frustrated.

6.6 Reflective note

The mixed and multiple methods undoubtedly contribute to the novelty and strength of this research. However, the iterative design of the work, raised awareness of the risk of bias. I would have to be mindful of the findings from Phase One and my emotional reactions to them as I approached the start up of Phase Two.

The major risk was that my previous experiences as a carer of someone with dementia would narrow my interpretation of the findings of Phase One during observation, and perhaps analysis. This was particularly relevant as my grandmother who had been living with dementia passed away after a long illness during the survey data collection, which meant I was still processing the grief of that loss as during Phase One data analysis. One of the motivations I had for this project was a visit to the local emergency department where I had accompanied my grandmother in 2014. The experience was deeply traumatic for her, and extremely distressing for my family and I as we felt her dignity had been stripped away and her safety compromised. Mindful of these experiences, and of the active grieving process I was engaged in at the time, I attempted to think reflexively about how these experiences may be influencing my interpretation of the data. I believe- to a certain extent- emotional reactions based on prior experiences are inevitable in research. These personal experiences can actually contribute positively to a project as long as the researcher is mindful of the risks of bias.

In the next chapter I will detail the steps I took to reduce risk of bias in observation and data collection.

Methods: Phase Two

7.1. Purpose and outline

This chapter provides a description of phase two of this project, which employed a qualitative approach using document review, observations, and semi-structured interviews.

The aim was to understand the systems and processes of providing care in the ED, and elicit staff perceptions of what could be done to improve outcomes given the current NHS climate. The secondary aim was to gain a deeper understanding of the patient and carer experience of accessing care in ED's to build on and supplement the information gathered by the survey in phase one.

The chapter starts with an introduction to the research teams at the two participating sites. Phase Two was split into two separate stages; scoping and familiarisation and primary data collection. The second section of this chapter describes the scoping and familiarization activities- document review and observations - which were undertaken prior to conducting interviews. This section offers a justification for the methods, and a description of these methods in practice. This section concludes with a discussion of the ethical implications of conducting observations in an ED setting where it was not possible to take written consent, and the potential impact of observation on staff behaviour, i.e. the Hawthorne effect (McCambridge, Witton, & Elbourne, 2014).

The third section describes the sample parameters and data collection process for the interviews, which constitute the bulk of the data collected in phase two. Inclusion and exclusion criteria and recruitment are explained and a critical reflection on the recruitment process is provided. The process of collecting data using the Yorkshire contributory factors framework (YFCC) - a patient safety assessment tool (Lawton et al., 2012; Yorkshire and Humberside Improvement Academy & Bradford Teaching Hospitals NHS Foundation Trust, 2012)- is described and the rationale for use is discussed. This section concludes with discussion of Framework Analysis (Gale et al, 2013) , and a description of how this method was used to organise and synthesize data. The

analysis section describes both the deductive and inductive approaches that were used to interrogate the data and identify inter-relationships.

This chapter concludes with a discussion of additional phase-specific ethical issues including the practicalities of involving PWD- in particular the process used for capacity assessment and safeguards to minimize distress. This section also includes the protocol that was established to facilitate the involvement of people who lack capacity but expressed an interest in participating, though this was ultimately not required in practice. The section concludes with a justification of the English language exclusion that was applied to Phase Two of the research as, like Phase One, this was an ethical issue.

7.2 Participating sites

This research was hosted by two hospitals in the South of England. The set-up of the research team from each hospital is given here for clarity.

7.2.1 Site one

The first site is a large teaching hospital. The ED has over 30 major injury or illness spaces six resuscitation beds, a minor injuries department, paediatric ED, and GP surgery on site. It is designated as a level II regional trauma centre.

The principle investigator (PI) for this site was a research nurse from the Clinical Research Network dementias and neurodegeneration team. This PI oversaw the conduct of research activities and was responsible for uploading recruitment data to the research management database (EDGE), but was not directly involved in the recruitment of patients or staff. As required by the ethics committee, a team of three ED specialist research nurses facilitated introductions to ED staff for potential recruitment. These nurses were also responsible for initial identification and first communication with potential patient and carer dyads to ensure private health records were not being accessed by anyone outside the care team. These research nurses have an office in the ED and regularly work clinical shifts in addition to their research role.

7.2.2 Site two

The second site is a small regional hospital with a smaller ED with 12 major injury or illness spaces, three resuscitation beds, and a minor injuries department. An out of hours a GP is based in the ED department. Paediatric services are provided by an in-reach team. The hospital is not designated as a trauma centre and does not accept trauma patients.

The PI for this site was an ED consultant with an interest in research. The PI was not directly involved in the day-to-day activities of this research. The research was supported by two research nurses from the Clinical Research Network dementia and neurodegeneration team. These nurses oversaw recruitment activities and managed uploads to the research management (EDGE) system. Recruitment of staff was supported by a band seven ED nurse with a particular interest in dementia, who championed the project within the ED. Patient and carer identification and first approach was undertaken by the in-hospital dementia team (n=10) consisting of care assistants and staff nurses who work across the trust.

7.3 Scoping and familiarisation

The scoping and familiarisation activities were undertaken by the researcher preceding the start of interviewing. As noted above, this stage consisted of document review and observations. This section describes the aim, rationale, and process for these methods.

7.3.1 Document review

The purpose of undertaking documentary review prior to observations and interviews was to familiarize the researcher with any policies, existing patient pathways, or other relevant research that was taking place at the participating sites. Undertaking document review- in conjunction with observations - prior to undertaking interviews is an accepted method of data triangulation in patient safety research (Dixon-Woods et al, 2009) and is a widely accepted method of data triangulation in research informed by ethnographic principles.

In preparation for the data collection the researcher contacted the PI, the research nurse(s), and the ED point of contact at each hospital. These key informants then supplied copies of any documents they felt would be relevant to the project. The documents supplied included;

1) Blank copies of triage assessment forms
2) Blank copies of screening tools currently being used in ED for;
    - Falls
    - Comprehensive geriatric assessment
    - Frailty assessments
    - Pressure spot monitoring
    - Catheter placement pro-forma
    - Neck of femur fracture pro-forma
    - Hydration/nutrition assessments
    - Delirium screening,
3) Hospital policies on intended patient pathways for older adults
4) Escalation policies for times of increased patient pressures in ED
5) Information booklets kept in the department for family and other supporters of people with dementia relating to community services
6) Information on other research being carried out at the hospital relating to dementia or safety in the emergency department

Each of these documents was reviewed for content and, where appropriate, compared to national or international guidelines of best practice. Any ambiguities or lack of clarity identified in these documents were raised with the research teams at the relevant site. These documents were then stored as part of the master site file for future reference. The content of the clinical documents and guidelines assisted the researcher- who does not have a background in clinical practice- in establishing familiarity with the ED systems and processes prior to undertaking observations. The documentary review was primarily for the benefit of the researcher and as such there is no explicit documentary analysis in the findings.

7.3.2 Observations

The aim was to familiarise the researcher with the operational environment in which the staff are working and to observe care practices first hand. Observations informed by ethnographic principles are an effective way to gather information about systems and cultures in a defined environment (Carthey, 2003). The relevant principles of ethnographic research which were employed for this project were underpinned by 1) a constructionist or interpretivist perspective of knowledge which enables interpretation based on individual experience and, 2) a focus on understanding culture through observation and description of activity (Draper, 2015). Additionally, this research is contextual (i.e carried out in the context where the subjects typically work) and collaborative (i.e. the participants are active contributors to the development of theory by sharing their interpretations of behaviours and cultures which are observed by the researcher).

This research was also informed by the 'human factors' approach to patient safety (see section 4.3 on patient safety) which looks beyond the practices of frontline staff and instead takes a full systems view of patient safety, seeking out sources of safety and risk across all levels of an organization's structure. A key element of this approach is the belief that the major source of risk to patients is not the skill of the individual staff providing care; instead risks to patient safety are - in large part - produced and influenced by how care is organised, administered and supported (Dekker, 2005). Given this approach, it was essential for the researcher to have a first hand understanding of the systems and process in the emergency department in order to identify those potential sources of risk or safety.

All observations took place in the ED's. Each hospital hosted four sessions of observation that lasted four hours each - for a total of sixteen hours of observation at each site. The timing of these observations was spread across day/night, weekday/weekend, and various shift changeovers to secure a 24 hour perspective. The researcher carried out observations at a number of places in the department including:

1) The entry and waiting room

2) Near the preliminary triaging area for patients arriving by ambulance

3) The minor injuries area

4) Major injuries and illnesses (known as ‘majors’)

5) The short stay units attached to the ED.

No observations were done in the resuscitation area. Observations were carried out in the hallway areas near triaging rather than directly within the triage area to ensure visibility of patient flow without being privy to private information shared during handover or assessment. The observations did not include close shadowing of clinical staff or direct observation of care delivery. As noted above, the purpose was to gain a deeper understanding of the way the ED functioned at a systems level and to observe how staff behave in this environment.

During each period of observations the researcher took between 3-7 pages of field notes on a structured pro-forma. This pro-forma has predefined sections for each area of the ED and allowed for reflections on the physical environment, ambient atmosphere, patient flow, staff behaviour and interactions in the department – see appendix ten for a blank example. The pro-forma is intentionally minimal in its format, and has no connection to the YCFF which guided the later data collection during interviewing. It was felt that using the YCFF during observation would introduce a risk of confirmation bias (Kahneman & Tversky, 1977), where the researcher could seek out or interpret behaviours and classify them as contributory factors. This was particularly relevant given the sequential nature of the mixed methods approach used here, where it was anticipated that the survey findings would directly inform the direction and weighting of the interview schedule. Pursuant to this, preliminary data from the survey had been analysed and interpreted prior to the initiation of observation. The researcher was aware that being exposed to these data- in particular the identification of practices or approaches which patients and carers felt lead to poor outcomes or experiences- could also potentially bias phase two data collection.

To minimize the risk of bias, the researcher completed a personal, reflective journal about the experience and any personal, situational or research circumstances that may have affected the data collection. These reflective journals enable a move towards reflexivity in practice. Additionally, the researcher recorded field notes with clear delineation between observable actions and the researchers' reactions separately. Observable actions were recorded in bullet form and any emotional reactions, judgements or commentary were recorded in parenthesis following that note.

Behaviours or actions that had been identified as problematic by survey respondents were highlighted in the notes to be explored in the interviews if the opportunity arose. This process of identifying contentious findings via the survey, confirmation via the observation, and seeking potential explanation in the interview highlights the contribution of the mixed methods approach. For an example of these observational notes see appendix eleven. For an example of how the observation notes were written into vignettes, see appendix twelve. The field notes have been included as qualitative data in analysis, however, the reflective journal was used solely assist with identifying potential personal biases so as to improve objectivity (Fontein, 2014).

These scoping and familiarisation activities ensured the researcher was able to ground the data collection that followed in observed practice to ensure the interviews remained focused, succinct and context specific.

7.3.3 Observations: ethical considerations

Observational research can play an important role in understanding complex systems and identifying areas for improvement as part of a services audit (Craig et al., 2008). Whilst good research practice typically requires participants to be informed, and a written record of informed consent to be kept, this is not practical for observational research in a busy ED setting. This was recognized as a potential ethical issue for this project. After consultation with the Ethics Committee (East of England-Cambridge Central- 17-EE-0227), the observations were approved, provided certain safeguards were put in place.

These safeguards included patients and visitors being informed that

observations were taking place in the ED both in writing- via signs posted around the department- and verbally on entrance to the department. For each session of observation between four and six laminated signs indicating, “observation is in progression in this department” were posted (See appendix thirteen for an example). Their placement varied, but always included a sign on the front door and reception desk, a sign by the entry to the ED (by the ambulance door), and a sign posted directly above or beside the researcher as they observed. The researcher also visited the receptionists and triage nurses before each session of observation to offer a brief re-introduction to the project aims and research activities to enable them to answer any questions that patients or visitors might ask.

During the observations, no patients or visitors indicated that they would prefer their interactions not be recorded. However, on two separate instances, the presence of a researcher observing in the corridor seemed to cause distress to patients waiting for treatment. These episodes of distressed behavior were characterized by calling out, crying, reaching towards the researcher, and moving in ways that could be interpreted as attempting to get off the trolley. While these patients did not verbally indicate their preference not to be observed, the researcher felt it would be appropriate to relocate to another non-visible area to reduce the distress.

Staff participants were given advanced notice of the observation dates and times in the brief introductory-message that was sent to the NHS emails of all staff in the department prior to the start of this project- it is important to note that while all staff has access to these email accounts they are not always routinely checked. In addition to the e-mail notice, posters were displayed in non-clinical areas of ED (i.e. kitchen, staff bathrooms, break rooms) to inform staff of the upcoming observations. Staff were given an “opt out” option- where they could indicate their preference not to participate. If they indicated this preference, their interactions with patients and other staff would not be noted. No staff indicated that they preferred not to be observed.

On the day of the observations, the researcher introduced themselves to

the nurse in charge of the department, asking where it was best to stand/sit in the department to minimize disruption. The researcher would also re-iterate the purpose of their presence in the department by asking the nurse in charge to share the information with staff throughout the period of observation.

With observational research there is always a risk that the presence of the observer in the research setting may influence the behaviours and actions of staff that are being observed- known as the Hawthorne effect (McCambridge et al., 2014). Though the original experiments which demonstrated the effect have been called into question, there is sufficient evidence to suggest that the presence of an observer has an impact on the behaviour or practice of the person being observed (Leonard & Masatu, 2006; McCambridge et al., 2014). However, critics argue that the impact of observation on behaviour requires consideration of the complex interaction between social expectation, learned behaviours and psychology, and therefore the idea of a 'Hawthorne effect' is over simplistic and thus unhelpful (McCambridge et al., 2014). Ultimately, the risk of Hawthorne effect compromising the data collected was not sufficient to justify requesting permission to carry out observations without notifying staff before the study. Importantly, Leonard and Masatu (2006) found that the Hawthorne effect wore off with time-observing clinicians resorting to usual practice despite the presence of an observer within a short period. Pursuant to this finding, the researcher arranged multiple sessions of observation at each hospital to allow the staff to become familiar with the presence of an observer with the belief that it could mitigate some of the potential Hawthorne effect.

7.4 Qualitative Interviews

The majority of data collection for this phase of research was undertaken via semi-structured interviews. This section begins with a rationale for using interviews, and then describes the sample, their recruitment; and the interview process. This section concludes with a discussion of some of the ethical considerations with qualitative interviews. As previously noted, in keeping with the mixed methods approach the structure and process of these interviews was

informed by the survey research and observations, which preceded the interviews.

7.4.1 Interviews

The objective of the semi-structured staff interviews was to gather detailed information about the personal experiences of those who care for people with dementia in ED. The objective of the interviews with patients and carers was to explore the recent experience of hospitalisation, and to identify where the patients and/or carers felt they were had been at risk of experiencing unsafe, or poor care. Interviewees were also asked to share experiences of good care they encountered to assist with the identification of positively deviant practices, which could be expanded or utilized more frequently to improve care.

Face to face interviews were chosen as the primary investigative method as they are an established and well-respected means of gathering data in social science research (Berg, 2007; Creswell, 2009; Kvale, 1996; Marshall & Rossman, 2006) Interviews enable a researcher to explore the "*quality and nature of how people behave, experience and understand*" as well as offering an opportunity to provide "*a detailed account of human behaviour and beliefs within the contexts they occur*" (Alshenqeeti, 2014, Pg 39). The benefit of conducting interviews face to face is that it allowed the researcher to gather this in-depth experience and participant perspective, while also providing an opportunity to consider social cues such as body language, voice, and changes in tone (Opdenakker, 2006). Finally, the semi-structured format chosen allowed the researcher flexibility to explore themes and ideas as they emerge (Alshenqeeti, 2014), while still providing a structure to the data collection which enables comparison across responses (Cohen & Crabtree, 1988).

Using interviews for data collection also has some potential disadvantages. These challenges are sometimes universal across all participants groups, and at other times are specific to respondent type.

Firstly, interviewing is time and resource intensive and it can be challenging to recruit (Gubrium & Holstein, 2001). These constraints meant the sample here was necessarily limited by the project timeframe and available

resources. This was not a major issue with staff interviews as saturation (Mason, 2010) was reached at 29 interviews. However, for the patient and carer dyads, the time required to recruit became a major barrier and resulted in a limited sample from this respondent group.

Another potential disadvantage of using retrospective interviews as a means of data collection for this particular project was the risk that patient participants might not be able to accurately recall their experiences. Memory loss is a key feature of many forms of dementia, and it is widely acknowledged that the experience of being in hospital can be stressful and traumatic for PWD and their carers. This trauma may have an impact on a person's willingness to discuss, or ability to recall, events (McNally, 2005; Peace & Porter, 2004). The researcher felt it would be unethical to involve individuals in this research if they would not be capable of contributing to the overall project- as it would be unfair to ask participants to volunteer their time if the data could not be used. To address this issue, the researcher used cognitive interviewing (Kohnken et al, 1999) as the approach to data collection for PWD and/or carers who may struggle with recall issues. For detail on the process of cognitive interviewing see section 7.4.5.2.

7.4.2 Sample

The sampling framework was purposeful, and stratified, to include active ED health care professionals in a variety of roles and levels of seniority. This section covers the inclusion and exclusion criteria that were determined prior to the start of fieldwork, and the recruitment approaches for both sites.

7.4.2.1 Inclusion and exclusion

- ***Inclusion- Staff participants***

  Staff must have been working at the trust at least six months to participate. Additionally, the member of staff must be directly involved in the care of patients in the emergency department.

- ***Exclusion- Staff participants***

  Staff who have been working at the trust for less than six months were not eligible to participate in the interview process. This was to ensure the respondents had sufficient working knowledge of the systems and processes of care at the hospital site.

- ***Inclusion- patients and carers***

  Participants must have experienced a recent admission to one of the two sites. The PWD must have been brought to the ED either by, or with, an informal carer. If a carer did not arrive with the PWD, but arrived shortly after, prior to their admission to the hospital or discharge from ED, and felt able to comment on the care received by their relative in the ED, they were permitted to participate.

- ***Exclusion- patients and carers***

  Potential respondents were excluded from the research if either member of the dyad was currently an inpatient at the hospital. Additionally, carers were excluded if the person they cared for or supported, died while in hospital. These decisions were taken to reduce the risk of causing distress during an interview.

7.4.3 Recruitment approach

7.4.3.1 Site One- staff

The hospital team and researcher agreed on a five-day period where the researcher would be present in the department to conduct interviews. Prior to these dates an email was sent to all staff in the ED introducing the research and offering an opportunity to participate. (*See appendix fourteen for an example information sheet for staff- only one is included despite distinct versions being made for each site. The content is identical, only branding differs*) Additionally, posters introducing the research were placed in the staff only areas of the department to highlight the research (see appendix fifteen). Eight interviews with various members of ED staff were organised for these pre-arranged days via

email. In addition to these pre-arranged interviews, the researcher would walk the floor of ED at the start of each interview day with the research nurse and highlight the opportunity to staff working. If any staff members expressed an interest in participating, the ED research nurse would cover the staff members' clinical duties for up to an hour to enable that staff member to participate.

One pre-arranged day for interviewing needed to be rescheduled as a result of low staffing levels and a lack of beds. These circumstances meant the ED was operating on 'Black Status' and staff were not available to be interviewed. This was the first scheduled day of interviewing, and the research nurses proposed that observational data should be gathered on this day rather than the following day. This suited the originally intended sequential order that had been slightly altered due to scheduling conflict, and therefore did not constitute a change in protocol.

7.4.3.2 Site One- Patients

Potential patient participants were recruited by the ED research nurses while the patients were in the Acute Medical Unit (AMU), or in general medical wards. The ED research nurses worked closely with the ED based frailty intervention team who review all ED patients with potential frailty. The frailty team keeps a record of all the patients that they review, and their standard assessment includes capacity assessment and cognitive status review. The frailty team continues to be involved with these patients throughout their stay in hospital, and therefore their involvement in identification was helpful as it prevented patients becoming lost to follow-up if they transitioned rapidly through the ED. Whilst the frailty team assisted with identification, the official approach and recruitment was done by the two ED based research nurses. Potential participants were given an information sheet and an opportunity to speak to the research nurse about the project (*See appendix sixteen- carer information sheet is include here. Distinct versions for patients were also made, but not included as only language identifying target audience differs between carer and patien*t). The patients and carers were then given twenty- four hours to decide (cooling off period) if they were willing to be contacted after they were discharged. If they

were willing to be contacted after discharge, they completed a 'permission to contact form" (see appendix seventeen) and the form would be given to the researcher after the patient was discharged.

There were two major barriers to recruitment at this site. Firstly, the recruitment process required a twenty-four hour cooling off period, which meant several (*number not recorded by ED nurses*) potential participants were discharged before the research nurses could follow up with them. Secondly, the requirement for both members of the care dyad to be out of the hospital excluded four potential respondents out of the identified nine as the patient had inpatient stays that persisted beyond the research period.

7.4.3.3 Site Two- Staff

The hospital team and researcher agreed on three days where the researcher would be present in the department to conduct interviews. These dates were arranged to coincide with dates when a Dementia Link Nurse was in the department as the matron. The intention was that the matron would cover clinical duties to release staff nurses and senior sisters to participate in the research. Prior to the first of these dates, an email was sent around to all the staff in the ED introducing the research and offering an opportunity to participate. Additionally, posters introducing the research were placed in the staff only areas of the department to highlight the research. Despite this e-mail being sent to all staff, no volunteers were identified prior to the first day of interviewing. On each scheduled interviewing day the researcher called the matron at 7am to check the status of the department and confirm suitability of researching that day. If the hospital was operating well, the researcher would arrive at 8am and the Matron would ask if anyone on staff was interested in participating in an interview. On two of the originally scheduled days, the department was operating at capacity and the matron was needed on the floor to assist with patient care. On one of these days the researcher was invited to attend and observe the site on black status, and on the other the interviewing was re-scheduled for a mutually convenient time.

7.4.3.4 Site Two- Patients

Patients from this site were identified and recruited by the Dementia Team at the hospital. This team consists of ten staff members ranging from band three care assistants to junior band five staff nurses and is overseen by two senior sisters. The Team covers the entire hospital, offering one-one intervention and support to patients with dementia from 8am-8pm seven days a week. The Dementia Team were given a one-hour training session by the researcher to introduce them to the project and demonstrate how to approach and recruit patients for the study. The intention was for potential participants to be given an information sheet and an opportunity to speak to the Team about the project. The patients and carers were then supposed to be given twenty-four hours to decide if they were willing to be contacted after they were discharged. If they were willing to be contacted after discharge, they would complete a 'permission to contact form' and the form would be given to the researcher after the patient was discharged.

Despite the large number of staff involved in identifying potential participants, patient recruitment was a challenge for this site. Ten patients were identified and shared their personal details with the dementia team to allow the researcher to contact them post discharge. Upon further discussion with the researcher, and receiving additional details about involvement none of the ten dyads were willing to participate in the period immediately following the hospitalisation.

In four cases this was attributed to the existing stresses of facilitating a transition in the patient's life- most frequently from living independently to living in a nursing home. The carers felt unable to commit to additional activities during this period of transition either due to burnout or uncertainty over the support they would be required to provide during this period. Two others commented that the hospitalisation had been particularly stressful and they were not feeling emotionally capable of revisiting the experience. Of these two, one was willing to participate, but only after eight weeks had elapsed, at which time the data collection for the project had concluded. A further two commented they did not

feel able to remember their time in ED, as a significant period of time had elapsed between the admission and discharge. The remaining two did not respond to phone called (x2) or emails and were assumed to be uninterested.

The significant number of refusals from this site suggests that there may have been miscommunications during the recruitment process. It is possible that the large number of people (n=10) involved in identifying and approaching patients may have meant the staff did not have sufficient information about the study to confidently recruit. Additionally, the members of the Dementia Team are not traditionally research active, and may have found the process of approaching patients for potential recruitment unfamiliar and uncomfortable. Furthermore, a system of recruitment stickers and tracking charts was proposed by the research staff at the hospital to prevent patients being approached multiple times by different members of the Dementia Team. However, the complexity of the system seemed to be off-putting to some members. Lastly, it is possible the large number of staff involved in recruitment may have contributed to a 'bystander effect' where the staff assumed others were recruiting and therefore they did not need to do so.

7.4.5 Process

7.4.5.1 Staff interviews

As indicated earlier, data from the preceding survey and observations influenced the data collection during interviews, as demonstrated in the interview schedule. Prior to starting the interview each participant completed a consent form (see appendix eighteen) In addition, the Yorkshire contributory factors framework (YCFF) was employed as a tool to guide data collection. In each interview, the respondent was shown the YCFF diagram (See appendix nineteen to view the summary diagram) and its purpose as a structured framework for guiding enquiry was explained. The staff would then be asked if they wanted to discuss a time 'when care went well', or a time when they felt 'care did not go well' (see appendix twenty for the full interviewing schedule). Depending on the preferences of the respondent, the interview would proceed

with the first example. The respondent was encouraged to tell the 'full story' of their chosen case (*either positive or negative*). Once this unstructured narrative was complete, the researcher would paraphrase back to the respondent to ensure clarity. Once this story was clear, the researcher would direct the attention of the respondent to the YCFF diagram and ask questions about each of the contributory factors to establish its potential relevance and discuss how that factor may have impacted the particular case that was discussed. During the interview, the researcher took notes on a structured data collection instrument (see appendix twenty-one for a blank copy).

Once the first narrative was complete, the researcher would invite the participant to share another case study- (*positive or negative dependant on their initial preference*) and repeat the process. As with the first case study, an unstructured narrative was shared, and then additional detail on particular contributory factors that impacted the episode of care was elicited using open ended probing questions. At the close of the interview respondents were asked about what they would like to see done differently and which practices they would like to see used more frequently in the ED to improve dementia care.

Use of this tool ensured a systematic appraisal of the safety (and quality) of care for each of the episodes of care discussed. The rigorous methods used to develop the YCFF (see Pages 72-73) added a layer of confidence that data collected would represent a comprehensive index of potential contributory factors from both proximal and distal sources that contribute to either poor care or good care.

However, the interviewing schedule also allowed for flexible exploration of emergent themes within the confines of the YCFF domains, and offered an opportunity to pose probing questions on care practices or interactions which had been highlighted as relevant by carers and patients, or observed in practice. This enabled data triangulation as well as offering an opportunity to explore potential explanations for observed phenomena, in line with a mixed methods design.

7.4.5.2 Patient/carer interviews

It is widely acknowledged that dementia has significant impacts on short-term memory, language and comprehension. Some PWD find the experience of traditional interviewing distressing if they have challenges with recall or word finding. Additionally, the experience of being in hospital can be stressful, anxiety provoking, and at times traumatic for both carers and PWD. These emotional impacts may have an effect on a person's ability to recall events accurately. Mindful of these potential challenges, this research used cognitive interviewing during patient and carer interviews. Cognitive interviewing has been demonstrated to improve recall when compared to standard semi-structured interviews and is widely used in forensic and legal forums (Kohnken et al., 1999). To date, its use in social research has been limited despite showing promise as means to promote accurate recall of events for a wide range of respondents including those with cognitive impairment (Milne & Bull, 2006). Cognitive interviewing is an approach that guides enquiry rather than a distinct set of procedures.

The main feature of cognitive interviewing is the iterative process that supports the respondent to recall details. A cognitive interview starts with the researcher guiding the respondent through a process of 'context reinstatement'- the purpose of which is to return the interviewee to the context of the experience. In this study, this was done using verbal description of the various physical environments the interviewee may have passed through during their time in the ED. The researcher then invited the respondent to recall the entire experience from start to finish in an unstructured narrative, which allowed the respondent a chance to highlight details that are pertinent to them, and to help the researcher understand the overall experience. Once the respondent completed their narrative, the researcher encouraged the respondent to go 'back to the start' and guided the respondent through the whole experience asking probing questions about the participant's feelings or experiences to gather additional details that may have been missing in the original narrative (see appendix twenty two for the full interview schedule for carers and patients).

7.5 Analysis

7.5.1 Staff interviews

Framework analysis was developed by Richie and Spencer and is frequently used by NATCEN - the UK National Centre for Social Research (Gale et al., 2013; University of Surrey, 2015). The method is used for both data management and interpretation as it allows for reduction and synthesis of data while enabling researchers to maintain the clear links to each individual story (University of Surrey, 2015). Framework analysis was particularly suited to this research as it allows both thematic analysis and case analysis (Gale et al., 2013). This enabled the investigation of positive deviant approaches in each individual example, while also enabling the broader thematic analysis to identify trends in the data that may notable across multiple case studies. The process of analysis consisted of both deductive and inductive approaches.

The process of analysis started with transcription and familiarisation. Each of the interviews was transcribed into a word document. The researcher completed all the transcription. Once the data set was complete, the interviews were read multiple times in their entirety- a step known as familiarisation in framework analysis (Gale et al., 2013). The first round of coding the data was deductive, using the domains of the YCFF as a priori codes. The data was migrated from the individual transcripts into an analytical framework in Microsoft Excel, based on the domains of the YCFF. Four frameworks were developed for this project- two from each hospital, one containing the examples identified as good care, and the other containing case studies of poor care.

The process here was modelled after steps of ‘coding’, ‘setting the analytical framework’ and ‘applying the analytical framework’ described by Gale et al (2013) and the University of Surrey (2015). The purpose of this initial, deductive approach was to identify trends from each of the sites and perspectives (positive or negative) based on the pre-established domains of the YCFF. At this point in the analysis, mini narrative vignettes were extracted from the frameworks to illustrate especially pertinent individual experiences.

The next phase of analysis was inductive. The data from the four separate frameworks were integrated into a single framework, and each column- which corresponded to a domain of the YCFF- was analysed to identify emergent codes. The data was interrogated in its entirety to create a more comprehensive understanding of the experiences of staff caring for PWD in the ED. A number of emergent codes were identified through this process of interrogation, and possible relationships between certain contributory factors emerged. A new framework was created which more accurately reflected the various influences that impact on care – directly from the perspective of those observed and interviewed. This new framework retained the external contributory factors domain, but merged and rearranged several other sub-domains from the YCFF into new inductively identified domains which more accurately reflected various relationships. The four main domains from the new framework and how they relate to the original YCFF sub-domains are below

Figure 29: Inductive and deductive coding frameworks

New Domain	Source from YCFF
Patient characteristics	**Situational factors**: Patient factors, task characteristics
Staffing	**Situational factors**: individual factors, team factors, **Local working conditions**: staff workload, supervision and leadership, lines of responsibility, management of staff and staffing levels **Latent: organisational factors**: training and education
Physical environment	**Local working conditions:** physical environment, equipment and supplies **Latent: organisational factors**: scheduling and bed management, policies and procedures **Latent: external organisational factors:** Design of equipment and supplies, external policy context
External contributory factors	**Latent: external organisational factors:** External policy context

The benefit of using dual processes of analysis (deductive and inductive) was the opportunity to organise and assess the data within the already rigorously established and defined contributory factors framework domains, while also allowing for a flexible exploration of emergent themes that were context specific.

7.6 Ethical considerations

7.6.1 Involving people with dementia

The decision to include PWD as a separate group of respondents was carefully considered. As previously noted in the Methodology chapter this approach is relatively novel as the majority of dementia research utilises responses by carers. This can be problematic as at times PWD do not share the same opinions and experiences as their carer and the use of carer data as a proxy fails to capture the experiences of PWD (Alzheimer's Society, 2017). Therefore, facilitating and encouraging the involvement of PWD is recognised as an important evolutionary step in dementia research and several studies have proved it is possible to facilitate successful participation with appropriate adaptions (Allen, 2001; Barnett, 2000; Mozley et al., 1999; Murphy et al, 2010; Wilkinson, 2002). As noted in the methodology chapter, it is essential to balance the desire to create opportunities for involvement while retaining commitment to ethical research practice and legislation such as the Mental Capacity Act (2005).

The key consideration in involving PWD in this research was establishing capacity. While it would have been inappropriate to automatically assume that a PWD lacked capacity to consent, it would be equally inappropriate to involve an individual without ensuring a capacity assessment had been undertaken in line with requirements set out by the Mental Capacity Act (2005). According to the Mental Capacity Act in order to have capacity, a person must be able to

1) Understand the information relevant to the decision they want to make
2) Retain the information long enough to be able to make the decision
3) Weigh up the information available to make the decision, and
4) Communicate their decision (Mental Capacity Act, 2005).

They further note that capacity should always be treated as 'decision specific'- meaning an individual's capacity is assessed relative to each separate decision they make.

Despite the efforts of the research teams at both sites, only one participant living with dementia was recruited for the study. The challenges with recruitment of patient and carer dyads from Site Two was explored earlier and

will not be revisited here. The participant was a member of one of the two care dyads recruited from Site One. The other PWD from Site One indicated they had no interest in being interviewed. Their carer indicated that discharge from hospital had necessitated a short term transfer to a nursing home and their parent was feeling distressed by the move and upset with their family for 'allowing' the placement to happen. They felt this distress was likely to be contributing to the unwillingness to participate. The researcher offered to follow up with the carer to check on the situation after a month, but a phone call and email both went unanswered and it was assumed the carer and PWD wanted no further involvement.

When offered the option of completing an interview alone or jointly with their spouse the participant with dementia indicated an explicit preference to be interviewed jointly with their spouse. Therefore, the inclusion of people with dementia without a carer was not ultimately an ethical issue that was faced during data collection. However, the participant with dementia wanted to sign their own consent forms rather than have their spouse act as a representative. To ensure the consent gathered from them was fully informed and valid, a capacity assessment was performed by the researcher who determined the participant had capacity prior to obtaining written consent.

7.6.2 Risk of distress

In addition to formal written consent, the researcher used process consent throughout the interview duration, observing the participants at all times for verbal or physical signs of distress. If any potential distress was noted during the interview the participants were offered the options of;

1) discontinuing the line of discussion
2) temporarily pausing the interview and resuming at a later time, or
3) ending participation outright.

These options were explained as part of the consent process at the start of the interview, and reiterated if there was any indication of distress.

One staff participant experienced mild distress during the discussion, but expressed their strong preference to continue with the interview when offered

the option to terminate. The researcher offered a short break, and then returned to the interview with the consent of the participant.

At the end of each interview session participants were offered signposting to supportive resources in case they experience delayed onset distress. This included the researchers contact details, the contact details for the local hospital Patient Advice and Liaison Service office, and the contact details for the Alzheimer's Society 24 hour helpline. Each participant received a thank you card and a photocopy of the signed copy consent form 72 hours after their interview.

7.6.3 English Language exclusion

Considering the demography of the local population in participant recruitment is essential in ensuring representativeness of the data and as such, an ethical consideration. An assessment by Hampshire County Council in 2015 found that 95.9% of people over 65 in Hampshire described themselves as 'white British' and listed first language as English. This suggests that limiting respondents to English only should not have a significant impact on the representativeness of the data for this region. However, it may limit the ability of these data to be generalized to areas where significant variations in language or ethnic background are present. This is further supported by the fact that an ability to speak fluent English is a pre-requisite for working in a clinical role within the NHS. Therefore the language exclusion would not have any impact on the sampling for staffing. As this was a doctoral study with limited timeline and budget, it would have been unfeasible to include people who do not speak English as the cost of a translator would have been prohibitive.

(See appendix twenty-three for the letter of HRA approval that was received prior to commencing data collection)

Qualitative findings

8.1 Introduction and purpose of the chapter

This chapter will explore the findings from Phase Two of the project- the qualitative research phase. It explores the data from twenty-six interviews (*twenty four nursing staff and, two physicians*) as well as data from thirty-two hours of observations carried out at two sites, and data from three patient and carer interviews. As noted in Chapter Seven, there is no explicit documentary analysis in this chapter despite the use of document review as a method. The purpose of the document review was solely to assist the researcher with familiarisation into the ED context.

From a process of inductive analysis - as described in the preceding methods chapter, four key domains were identified[5]

1) Patient characteristics
2) Staffing (including training),
3) Immediate physical environment, and
4) External contributory factors.

Greater emphasis is given to the sections on patient characteristics and staffing as these are most applicable to answering the research questions (see page 1 for research questions).

The chapter is then divided as follows. Section one will discuss patient characteristics that impact a person's experience of care. It highlights the role of; communication ability (*both expressive and receptive*), emotional state, acuity of presenting condition, the abilities of the patient- with a particular focus on mobility- and the availability of family support.

Section two focuses on the ED staffing. There are five subsections: staffing levels; skill mix – incorporating specialists such as dementia support workers and frailty teams; nurse leadership and the effect on culture; formal and informal training; and the emotional impact of care-giving.

[5] For details on how the data collected using the YCFF was merged and re-organised into these four domains, see pages 148-149

Section three is dedicated to the physical and social environment of the ED. The impact of the physical environment (e.g. lighting, acoustics and physical layout) is already well understood. This section therefore focuses on the interaction between staff and the built environment, highlighting the impact of design on care. Access to 'comforts' such as food, drinks, toilet facilities, entertainment and comfortable seating are detailed, alongside staff attitudes to such comforts

Section four is devoted to the external factors that can impact on the ability to provide good dementia care in the setting. Addressing these complex, and multifaceted factors lay outside the remit of this project; however, it would be challenging to provide an accurate reflection on the state of dementia care in ED without revealing the impact of external factors.

Throughout this chapter, inductively derived vignettes are provided to help illustrate the lived experiences of PWD in the ED. These vignettes portray examples of 'good care' and of 'poor care'-as determined by respondents. They were derived from a triangulation of data sources including interviews and observations.

Throughout this chapter direct quotes are used to illustrate key points. At times the language of these quotes could be considered insensitive or abrasive. In order to ensure authenticity, these quotes have been presented directly, and without adaptation to remove potentially offensive terminology or to adjust syntax. Additionally, the chapter presents examples of self identified 'poor care'-which at times includes reflection on the respondent's own errors or shortcomings. One example from this chapter disuses the experience of being sexually assaulted by a patient. The emotive content of these direct quotes and examples adds to the value of this research- however, it also elevates the ethical imperative to ensure confidentiality as staff participated with assurances that their feedback would be non-identifiable. For this reason, certain details about the operational structures and governance models at the sites, which would normally be given for context, have been deliberately withheld. Each quote is given a unique identifying tag which indicates which site (S1 or S2) and

which interview (#1-14 for Site One and #1-12 for Site Two). The patient and carer interviews are not labelled with site identifiers due to the limited number of participants. For staff interviews, details on the respondent's position are given after their interview number. The only exceptions are when details about the job would identify the respondent.

8.2 Patient characteristics

Patient characteristics, which impacted staff ability to provide care, included;

1) The ability to articulate needs using expressive communication and to comprehend and retain information using receptive communication
2) Emotional status
3) Medical acuity
4) Physical mobility and the desire to mobilise
5) Presence or absence of family support

Each is now explored below.

8.2.1 Communication

A key staff issue was obtaining an accurate medical history from a PWD who arrives in the ED without supplemental information. Staff may not have easy access to community or primary care records, and therefore are reliant on a patient or carer reported history until other records are available. This can be a challenge when the patient arrives alone and is unable to give a history. A Site One frailty nurse working remarked that when taking a history from PWD one must always be cognizant of potentially inaccurate information and warned that a patient may be disingenuous: *"the first thing you have to come across is their dementia- you are going to get incorrect information, they are distressed…they want to tell you what they think you want to hear, and you have to be aware of that*" (S1/11- frailty Senior Sister). A physician from Site Two was rather more direct stating "*Patients can sometimes give you a history that is in no way reliable or reflective of what the problem is*." (S2/4-Physician). Staff reported that it is sometimes possible to tell that a PWD is unable to give an accurate history, but other times the patient's self-reported history is taken as correct until it is

later discovered to be inaccurate. One physician reflected "*If it's obvious you can't rely on a history, [that's alright], but you can be very much led down the wrong path by someone who sounds like they know what they are talking about*." (S1/12- Physician).

This inability to give an accurate history can increase a patient's risk of avoidable harm in several ways including a potentially inaccurate diagnosis and risk a potentially unnecessary admission. A physician from Site One shared an example of a patient whose neck of femur fracture, they feel, was missed twice due to inaccurate history sharing. This patient was an older woman living with dementia who visited the ED twice in the course of two weeks complaining of knee pain. At both visits she was assessed and sent home with a diagnosis of 'no bony injury to the knee'. However, on a third visit, a pelvic x-ray showed a fractured femur that had caused referred pain to the knee. This case became subject to an incident review and the physician stated "*This lady was able to remember what happened, but was unable to articulate with sufficient clarity that it raised concern about the clinical possibility of what the actual injury was…I'm not sure if that's because of what she said, or how what she said was perceived…What she explained was taken at face value*" (S1/12-physican). The need for more investigations to supplement potentially inaccurate self-reports can increase the length of time patients spend in the departments and the number of diagnostic tests required. A physician from Site One noted that patients who are unable to articulate their history or current condition are more likely to be admitted as a precaution as the ED does not have time to do a full assessment and treatment within the four hour 'decision to admit' target. The doctor remarked "*If the patient is unable to communicate, and there is no paperwork or person who can explain what the problem is, they get admitted*" (S2/4-physician*)*.

Vignette 1: Inability to articulate cause of distress
A patient with dementia was brought into the department. No beds were available so he was placed on a trolley in a corridor. He became very distressed, crying and trying to get up and off the trolley. The frailty nurse- visiting another patient in the department- observed his nurse regularly putting his legs back onto the trolley and telling him to stay where he was with visibly increasing frustration each time. Eventually the ED nurse tilted the trolley so his head was down and feet up to reduce the likelihood of him getting out of bed. This further increased his distress and the frailty nurse came to investigate when she heard him crying and shouting. She discovered he had been incontinent and the bedding was wet from his knees to his shoulders. He had been trying to get off the wet and cold bedding but was unable to articulate the problem

Source: interview

Similarly, nurses working in the ED from both sites reported that impairments in expressive communication affect their ability to provide good nursing care for PWD, especially when the patient is unable to articulate their needs. Several nurses reported it is harder to provide good care when the patient can't or won't articulate their hunger, thirst, need for the toilet, or current levels of pain or discomfort. One noted "*Sometimes the patient's don't tell you what they need -they just sit there in bed, they won't say they need to go to the toilet, they need feeding, they are hungry…"* (S1/8-staff nurse) and another commented *" it's an issue that we have…we can't always figure out what's wrong with the patient if they can't tell you, so personal hygiene- toileting and stuff- can be the problem, but you don't know that, so they end up wetting themselves and laying in a wet patch for a while…"* (S2/1-staff nurse).

Some PWD have significant impairments in their ability to comprehend or retain information- especially in short term memory. This can be a challenge for ED staff, some of whom highlighted the challenge posed by patients who try to mobilize when it is unsafe to do so. Staff from both sites indicated a particularly challenging scenario is patients who have neck of femur fractures who sometimes try to mobilize after receiving a spinal block that masks the pain This was observed twice during observations, and noted as a concern at both sites through reports from three separate staff. One noted, "*the trouble with a block is that it can be so effective that the person with dementia tries to get up and walk*

around with the broken hip and then falls and breaks the other one. On the one hand, they need analgesia, but on the other, they do need a bit of pain to remind them to lay still." (S2/4-physician). A nurse noted the same phenomenon stating *"if you've got a patient who has neck of femur fracture- and they are confused, and they can't feel the pain, they'll want to stand up, they, want to move, … you are constantly trying to keep them in bed" (*S1/9- Nurse). Another nurse indicated that this caused her considerable stress, saying "*I find it extremely stressful- trying to explain to someone that 'you need to stay where you are, I know you don't understand me, but you need to stay where you are'*" (S2/1-nurse).

Other times, it is not dangerous for the patient to mobilize but their moving around the department poses a challenge for staff or upsets other patients. Several staff shared case studies where PWD were walking around the department, shouting at, or attempting to climb into bed with other patients. These actions interrupted doctors and nurses who were attempting to provide care to others. One nurse recalled a patient who was brought in with sepsis whom, after receiving IV antibiotics, was able to mobilize and wanted to go home. They said "*sometimes they come in and they are feeling very poorly, so we give them the antibiotics and they start to feel better so they think, I'm feeling better, time to go now- I'm ready… that happens quite often*" (S2/8- senior nurse). The nurse later explained that while it was possible to explain to the patient why they needed to be in the hospital, the patient could not retain the information and would repeatedly try to leave the department. They explained, "*She didn't remember what she had been told… she could be reasoned with at first, but not retain the information. It eventually caused frustration*" (S2/8- senior nurse).

Impairments in receptive communication can also make it difficult for staff to get consent for interventions. A nurse gave the example of a patient who became violent while she tried to help them change from their clothes to a hospital gown as the patient had not recalled giving consent to being undressed. She later reflected that this was not an unanticipated outcome, because "*If you*

get someone with dementia who is very private and you try to take their clothes from them- even if you are saying you are in the hospital- they may not understand and you are going to end up getting hit" (S2/13- Frailty nurse).

8.2.2 Emotional state

The patient's emotional state on arrival in the ED has a significant impact on staff's ability to provide effective care. If the patient is distressed, agitated, or angry they are considered harder to care for and appear more likely to have a poor outcome. The experience of being taken from home and brought to the ED in an ambulance is acknowledged as disorientating and distressing for many patients. One nurse noted …"*They are put into an ambulance trolley, shipped off in an ambulance, dumped in our ED, and they are looking around thinking, Oh my god, where am I? It must be really, really stressful for the patient*" (S2/8-nurse). This sentiment was also echoed by one of the physicians who said *"it's often too late by the time they get here, because they have been whisked out of their home by a noisy ambulance, in an uncomfortable bed, with a painful condition*" (S2/4-physician).

Vignette 2: Patient with Dementia with Lewy bodies being aggressive
A man living with Lewy bodies dementia arrived in the ED overnight. On admission he was undiagnosed. Large, mobile, and very strong physically, he was brought to the department by police after an episode of severely disturbed behaviour at home. He was distressed and volatile when he arrived in the department and his behaviour escalated further overnight. The department was extremely busy- queuing out the doors - and the nursing team overnight were all junior staff nurses. Because of his distressed behaviour and aggressive mannerisms it was not seen as possible to undertake any investigations to determine if there was an organic cause of the agitated behaviour. Several of the nursing team became frustrated with his behaviour and responded sharply to him, which escalated the tensions. As the situation deteriorated, security was called to assist the nursing staff- the presence of two large men in high-visibility jackets caused further agitation and the man attempted to choke one of the nurses. He was held down by two security guards and a nurse to be sedated. Because of his agitation, four doses of sedation were required before he was deemed calm enough to release the physical restraints. His trolley was tilted so his feet were higher than his head to prevent him from getting out of bed and he was left under the supervision of the two security guards with minimal interaction from the nursing staff for the rest of the night. The dementia team was called to see him first thing in the morning and found him tilted on the bed, lying in urine and blood covered clothing and bedding. They spoke to him and got him clean

and sitting in a chair. They were eventually able to take blood and urine samples to enable investigations that showed an infection. He had just been settled when the decision was made to move him to acute medical unit (AMU) to prevent a 12 hour breach. The transition caused him to become unsettled and agitated again. On arrival at AMU he attacked another member of staff causing a serious injury and was sedated again. He was later transferred to a locked psychiatric facility. The dementia team felt the situation could have been prevented with more compassionate care and better understanding of dementia with Lewy bodies.

Source: Interview

Nurses indicated that they can be apprehensive about approaching patients who are highly distressed on arrival in ED as it can be challenging to de-escalate and there is an increased risk of the patient becoming violent. One nurse reflected on a patient who had arrived there, saying "*she arrived screaming, and that puts everyone on panic mode, because you can't placate her, you can't calm her down*" (S2/8-nurse). The patient from this example was violent towards the staff, and the nurse described the patient trying to hit the nurses with her walking stick and screaming at them before they could introduce themselves. Another nurse describing a similar situation with another patient, but her comments were empathic: "*she's violent because she's terrified*!" (S2/6-nurse).

Some nurses felt that they lacked the right skills to manage emotionally distressed patients- especially when they become aggressive. A frailty nurse who considered themself a specialist in intervening in these situations remarked "*aggressive patients are more challenging- some of that's educational, some people take personal offense to it, but it's about learning ways to manage that, to sort of take a step back, there is no point in being combative*" (S1/6- frailty nurse). This was echoed by a member of the dementia team from the same hospital who recalled an incident where she was called to the ED to assist a PWD who was psychotic. The ED staff were relying on physical and chemical restrain to manage his distressed emotional state. She recalled, "*there was a significant fear of getting involved and a poor understanding of mental illness and dementia*" and "*some of the members of staff had taken the abuse he was shouting quite personally*"(S1/3- Dementia team). She noted that intervening in

this situation required a gentle, relationship-building approach, which recognized and acknowledged the fear and disorientation the patient was feeling.

8.2.3 Acuity[6]

The ED is principally designed to provide emergency care for people who are acutely injured or unwell, and consequently patients who are not acutely ill receive less attention and nursing input. Many PWD require support above and beyond what would typically be required for the presenting complaint while they are in the ED and this can pose challenges for staff if the patients' medical acuity doesn't warrant one to one attention. One nurse said, *"If someone is very clinically unwell, it's not the dementia that's the problem. But, if they are here for a minor injury, and it's a busy day shift, that's when things go wrong" (*S2/6-Nurse). Another commented "*they are always a low priority until they become a problem, or a more urgent problem than the next person- if there is no medical need for a person to be in ED, they won't get priority."* (S2/10-Nurse).

One nurse described an example where four nurses were called off the floor to assist with applying temporary plasters to a PWD who had broken their leg and was distressed by the procedure of plastering. They commented, "*it's quite a difficult time because [they] needed a lot of resources to help her, and then you still have the other patients to try and keep on top of*" (S2/10). This is a vivid example of a patient whose actual needs were far beyond what would usually be expected for the type of injury or illness. Another nurse described a scenario where a PWD was being held in the department overnight due to lack of transport. He was being assessed for possible head injury after an un-witnessed fall. The patient had been declared medically fit, but was exhibiting behaviours that challenged the staff and distressed other patients. The patient was eventually sedated for the safety of everyone involved. The nurse in charge during that incident reflected;

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[6] Acuity is defined as the measurement of the intensity of nursing care required by a patient

> *…from my perspective, being in charge, it's an absolute nightmare….. you have got patients that, one, shouldn't be in the department, they should be able to be discharged, and be back in a relatively safe environment* [the nursing home]. *I didn't feel we could safely, or as safely as I would have liked, care for [them] that night because [s/he] was a very, very high falls risk, and it was- a night like that- when you are incredibly short staffed- [s/*he*] was pulling staff that I needed to be looking after the sick patients- having to deal with [them] as a patient, when in an ideal world we could have discharged [them]*" (S2/9- senior nurse).

Alternately, when PWD arrive at the hospital and they are acutely ill, it is easier to ensure they have the support they need both medically and psychosocially. A nurse from Site One described an incident where a PWD was brought to the department after a road traffic accident, and because they had been labelled a 'trauma' there was a dedicated team available to provide the care and support the patient required to maintain their calm and orientation in the department. They commented the "*big difference with having extra staff there is there is always someone there to talk to her, explain what is going on" (S1/6-nurse).* They further explained, *"By that time, s/he was put on a trauma board with a collar on. That's very, very frightening for anybody- never mind for someone who is a bit confused- so having time to talk to [them], to say why [they're] having that…cause you know you aren't just telling them once, you are telling them repeatedly*". The nurse also commented on the benefit of having additional staff resources during transfers, saying "*there were questions about [their] cervical spine that had been damaged, so [they] went down to CT, but there were lots of staff to go down to CT- so again that wasn't an issue*" (S1/6). Because this patient was seen as having a legitimate need for this level of intervention, it was easier to ensure the staffing was allocated to them.

8.2.4 Ability and mobility

Nurses described patients who are fully dependant as the easiest to care for, whereas PWD who are physically independent (and mobile) and require high levels of assistance are the most challenging. One nurse commented "*Sometimes its easier to care for patients who are acutely unwell and have higher dependency because you just 'do it for them' rather than supporting*"

which takes more time (S2/7- staff nurse). However, the nurses do note that patients who are fully dependent can sometimes have poor experiences of care if there are other acutely ill patients in the unit who require high levels of input. In particular, continence care is highlighted as a challenge, as several nurses described their discomfort with having patients left in soiled incontinence products sometimes for several hours. One commented they find it uncomfortable knowing there are "*people waiting for hours and hours not eating and drinking or able to use the toilet"*. They continued: *"if someone has had an incontinence, they have often been calling for ages*" (S1/13 senior nurse). These highly dependant patients are also perceived as less likely to mobilize independently, which means they are perceived as requiring less supervision. However, as noted above, these patients have higher risks of not receiving the care they require if they are unable to articulate their needs. Another challenge with this group, according to one of the nurses, is overcoming the desire to perform tasks for the patient because it is faster, thus creating dependency where there is none. They commented, "*when they come in, the paralysis of pyjamas comes on. We look at them and think, everything needs to be done for them!*" (S1/9- senior nurse).

The most challenging patients for the nurses are the ones who require assistance and are confused, but who are mobile. These patients are perceived as being a high falls risk, and can be disruptive if they enter restricted or unsafe spaces. A nurse described the challenge she had with a patient with these characteristics, saying "*we were teetering on the edge of things going wrong- he didn't want to lay on a trolley, he didn't want to sit in a chair, he was used to wandering in his rest home and he just wanted to walk around the department and talk to people- but when it's that busy you can't do that!*" (S1/13 nurse). Another nurse stated, when it is busy it can be challenging to ensure patients who are assessed as a falls risk stay in bed, saying " yo*u end up chucking patients back into bed… it's not what you want*" (S1/5 staff nurse). During the observations at both sites, it was apparent that supervising patients who are assessed as 'unable to mobilize without assistance' was a major challenge. The

nurses were observed using a variety of strategies to address this including; placing a marker such as tape on the curtains to alert colleagues that the patient requires additional supervision, moving the patient to a chair near the nurses station or moving the patient to a more visible bay. Additionally, during interviews some staff reported that, on rare occasions, they either sedate the patient or assign someone to sit with them one to one.

8.2.5 Availability of family support

Whether a patient has family with them in the ED can play an important role in determining their experience of care. It is clear from these data that the family can be information stewards, support activities of daily living, and provide care and companionship to the patient while they are waiting. It is important, however, to recognise the potential strain that the family is experiencing and be aware of family dynamics.

Families often play a pivotal role as information stewards when the patient has dementia. Healthcare staff can sometimes access medical history through notes, but they often find it more efficient and helpful to take a verbal history from the patient or family member. As well as sharing relevant medical history, nurses frequently rely on family members to provide social history and help interpret behaviours. The important role of family was noted during observations and also commented on during in a number of 'good care' examples. During observations, a physician was heard telling a patient "*I've spoken to your granddaughter, very helpful'* (S1-OBS) and a nurse was overheard talking on the phone to a family member asking for information about the patient's normal cognition and mobility to assess the level of current impairment (S2-OBS). One of the nurses commented that while they are able to provide good care to almost everyone, it's helpful to have the personal insight and individual support from the family. They stated *"it's always helpful to have family around…"* as without them " *I am relying on my skills as a nurse and as a good human to be able to manage that situation, rather than knowing that person and knowing how to relax them*" (S2/5 nurse). Another nurse reflected on an interaction when a family member told them *'don't give her a glass, she'll*

throw it!' (S2/6 nurse) which assisted them in caring for the patient and helped keep the department safe.

In addition to being information stewards, family can also play an important role in providing non-medical care and support while the patient is in the department. Several staff reflected on the benefit of having family involvement; while they were able to focus on the 'medical' tasks, knowing that a more holistic approach to care would be taken by family. Staff frequently remarked that confused older patients need someone to stay with them continually to facilitate their reorientation- something the staff may not be able to accomplish. One health care assistant (HCA) remarked on a case where a patient was violent and extremely distressed which prevented physicians from carrying out a painful, but necessary, task of realigning a badly broken bone. When the patient's son arrived, the patient calmed immediately, and the staff were able to provide medication and complete the realignment of the fracture. The HCA remarked "*When s/he had a familiar face around, s/he was good as gold"* (S1/14 health care assistant).

Vignette 3: Unannounced family departure contributes to iatrogenic harm
An older man with dementia was brought to the department with abdominal pains. He was assessed as being a moderate falls risk. His family was with him in the department. The nurse who was looking after him was newly qualified and had been working in A&E for less than a year. The patient was visited by a phlebotomist who raised the bed and lowered the bed rails to make it easier to draw blood. Immediately after the phlebotomist left the doctor arrived to do an assessment. When the doctor departed, s/he left the bed raised and the sides down as that is how it was when s/he arrived. The family went to get coffee and did not mention their departure to the nurse responsible for the patient. Shortly after the family left the patient needed to use the toilet. He had been instructed to use the nurses call bell if he wanted to get out of bed but either did not understand, or did not retain this information. He attempted to mobilize from the raised trolley, but slipped from a considerable height- fracturing his pelvis and his C2 vertebra. When the family returned the wife acknowledged that he had been falling regularly at home, but she had not wanted to bring this to the attention of the medical staff as she feared they would be labelled as 'not coping' and her husband would be removed from her care in the community. The nurse responsible for him later said had she known of his history of falls, she might have '*kept a closer eye on him*' and told the family to notify her if they left the department. Prior to the accident the patient had been deemed medically fit for discharge. Post accident, he was admitted to the hospital for

reconstructive surgery on his hip and rehabilitation of the vertebral fracture.
Source: Interview

While family can play an important role in acting as a conduit for information or an advocate for the patient, many find the experience of being in ED overwhelming. In several of the 'poor care' case studies, a failure to recognise or react to family strain contributed to poor experiences of care for the patient or the carer. In one case- highlighted in vignette three - the wife of a patient had withheld information about her husband's condition (frequent falls at home) because she was concerned that her husband would be removed from her care. The nurse reflected "*I think she was a bit worried about saying [he had been falling at home], because she didn't want him to come in she wanted to be able to look after him*" (S2/11 staff nurse). In another case, a patient had been brought to the department after an incident of domestic violence at home. The nurse undertaking the assessment quickly realised that his wife needed 'care' just as much as him because the situation was so distressing for her. The nurse commented "'s*he was going through the mill a bit…She was feeling guilty and trying to excuse her husband's aggression…She wasn't willing to share if the aggression was physical or verbal- didn't want it reported*" (S1/11). Another frailty nurse commented that they frequently see patient/carer dyads in the ED with ambulatory conditions that could be effectively treated in the community but the carer is no longer able to cope. They commented "*I see a lot of people come in with carer strain, because they just don't know where to go*" and "*people will say- my mum can't come home today, I just can't cope anymore*" (S2/12-frailty nurse).

8.2.6 Conclusion

This section has discussed some of the key patient characteristics that are linked with an increased risk of a poor care experience in an ED. Patients with impairments in receptive and/or expressive communication have an increased risk as they may; be unable to share accurate medical history, mobilize in ways or areas that are unsafe, not retain instructions given for their own safety. Patients who arrived distressed to the ED or who cannot be

reoriented pose a challenge, as staff may not have the time and resources to provide one to one support. Patients who are medically fit, or considered low acuity, may have poor care experiences if their dementia causes behaviours which challenge the nurses. Family carers can play an important role in caring for patients with dementia while they are in ED, acting as information stewards, conduits for both medical and social histories, and providing personal interpretation of behaviours and actions. The family can however be experiencing significant strain or stress as a result of the dementia, the illness, or a combination of the two. Recognizing the characteristics that increase the risk of a patient having a poor care experience may help with early identification of individuals who could benefit from intervention or transfer out of the department.

8.3 Staffing

Staff play an essential role in determining the outcomes and experiences of ED patients. Several key aspects of staffing that impact the experience of PWD in an ED include; the number and skill mix of staff, the use and integration of specialist teams such as frailty or dementia teams, and the role of senior leadership in determining the organisational culture. Other staffing considerations include the training that staff receive on dementia- both formally in higher education settings and on the job- and the emotional impact of nursing people with dementia. This section will identify challenges and opportunities for improvement.

8.3.1 Staffing levels and skill mix

The most frequently cited frustration for respondents was the regularity with which they are required to work without a full staff rota. In the 'poor care' scenarios the most consistently quoted contributory factor was insufficient staff to appropriately care for the level or acuity of patients. Staff reported that the departments frequently struggle to ensure nursing rotas are filled, and failures to recruit mean the department runs with a skeleton staff or agency nurses supplementing the rotas. They said *"there just aren't enough staff… it's sad isn't*

*it, when you can't do the job you want to do, and you don't even really feel safe" (*OBS1) and *"There just aren't enough staff…there is never enough" (S1/1 nurse*). Another nurse commented, *"They* [the hospital] *would rather run a shift short staffed than call an agency* (S2/1 nurse*).* Others stated that even when the shifts are fully staffed, they sometimes do not have enough staff given the volume and acuity of the patients who arrive. They said, *"We were fully staffed, 22 people in the department, but there still wasn't enough people to provide good care for all the patients that were in…there never is*" (S1/14 Health care assistant). A member of the frailty team who regularly practiced in ED commented on the nurses' workload saying "*I feel sorry for them, they are pulled in every direction, there aren't enough of them for the levels of work*" (S1/13 frailty nurse). Staff report the biggest challenge with understaffing is the impact is has on the ability to provide holistic care and early intervention in deteriorating patients. One nurse, commenting on shifts where standard nurse/patient ratios are not met, said *"sometimes you are busy and you tell someone 'listen I'll be there in five minutes, and that five minutes is too long for them and they suffer the indignity of incontinence, and I feel awful*" (S2/1 nurse). Another commented, *"calling out is generally a warning, it's a precursor… its a sign of agitation and distress and if we don't address it, what will start as verbal calling out, will become physical attempts to leave… but you are firefighting- unless it's an immediate risk to safety, it's not perceived as a priority*" (S1/12 consultant). The lack of personnel is a safety concern for many staff, with several expressing a concern that they are unable to keep patients safe given the pressures they face. One commented, "*we are a little bit British about it…. we say we'll crack on, we'll cope… last winter showed it, this winter will show it… I don't know what has to happen for them to see...it's not safe*" (S1/6-Nurse).

In comparison, the most consistent theme which emerged in the 'good care' (positive deviant) examples was that at the time of the episode of care the department had enough staff to appropriately care for all the patients who were there or the staff had access to a specialist team who could provide super-

numeracy[7]. There was a sense that appropriate numbers of staff meant they were able to meet the holistic needs of the patient while also maintaining effective flow and ensuring patient safety. Reflecting on an episode of care that went well, a nurse said "*It was lovely, it was really nicely done- one of those things when you think, yeah we did alright! But had that been a busy day, it wouldn't have happened*" (S2/6 nurse). Another respondent shared an example of a patient who was extremely distressed in ED but who responded well to a particular care aide. They explained how the staff shifted around responsibilities to ensure this care aide was able to stay with the patient throughout their stay in ED and eventually got the patient to sleep despite her initial distress. They commented that while they were very proud of the outcome, "*we got lucky that day- if it had been busy in the department it just wouldn't have been possible*" (S1/10 - student nurse).

Vignette 4: Multiple high acuity patients

A senior nurse (Band 6) was working in a busy A&E department. This nurse was responsible for beds 1-5 in a major illness area ('majors'). One of their patients had moderate dementia and was extremely disorientated. This patient was walking around the department and calling out. The resuscitation area was full, but a major trauma call had just been announced and two patients had to be moved urgently from resuscitation to majors to free up space for the new arrivals. Two resuscitation patients were transferred to the majors area and assigned to the senior nurse on duty. It was felt the senior nurse was the only one who could medically manage the two transferred patients as both were on intravenous drugs and one was unconscious with his breathing supported by a mechanical ventilator. The man with dementia wasn't seen as acutely ill, and was assumed to need minimal nursing input. The nurse recalls feeling anxious caring for two patients who both should have been in resuscitation- and guilty for not providing good care for the patient with dementia who was disorientated and confused. Eventually the patient with dementia began trying to climb into bed with other patients, which caused distress. At this point, the nurse alerted a bed manager and asked for rapid intervention or assistance. After approximately an hour the bed manager was able to move the patient with dementia to a medical ward. While the nurse felt this was ultimately a good outcome, preceding the intervention of a bed manager they had felt a great deal of anxiety and were frustrated that the situation had to deteriorate into a crisis before assistance was offered.

Source: Interview

[7] Defined by McGowan & McCormack, (2003) as being additional to the usual compliment of staff.

In addition to the number of staff, it is important to consider the skill mix of the staff. In particular 1) the balance between junior or newly qualified members of staff and senior staff and 2) the balance of specialist frailty or dementia staff and regular ED staff. Senior staff such as band seven nurses, nurses in charge, and matrons commented that having a large number of agency or newly qualified staff can make it harder to provide good care as the senior staff are trying to teach and supervise while also providing care for patients. This is particularly notable if the agency or junior staff are not fully qualified to carry out tasks such as IV drug administration. One commented;

> *"We are getting in the nurses now who have just qualified, and that's the hardest part, there used to be a policy that you had to do 2 years as nurse before coming here, now within 2 months you are in A&E… … so [as a senior nurse] you are not only managing your own patients, you are also looking after them- they may not be IV trained, so you are doing their IV's for them, or drug competencies- so sometimes you end up doing 1-10 with an assistant. The skills mix is quite challenging some times"* (S1/9 senior nurse).

This same nurse described a shift the previous week where they were working in a 20 bed 'majors' area with 23 patients with two newly qualified nurses and two agency staff.

Another senior nurse- an advanced care practitioner- commented on the impact of having only one or two senior nurses on shift saying "*even if there are other staff members around, they tend to be other juniors*", and *it just gets you stressed, and doesn't give you the opportunity to just take 2 minutes to alleviate your own stress"* (S2/5 ANP). Some staff felt that as the pressures on ED increase, the more junior and less skilled members of staff are asked to take on additional responsibilities. One frailty nurse commented "*we are always trying to work in different ways, work with what you've got, they've up skilled the healthcare workers to do the investigations at the front door to free up the trained nurses to focus on 'skilled nursing*'"(S1/12 frailty). While this streamlines care processes, it can also reduce the number of staff available within the department to provide holistic care such as food, drinks, and companionship. Additionally, it increases the risk that staff may find themselves in situations that are beyond their capabilities. One respondent described a situation where they

were sexually assaulted by a PWD while they were assigned to provide one to one care for them. The respondent said "*He was just a randy little old man!...I was able to manage because I am experienced and older…. I just wonder what a younger [care assistant] would have done…*" (S2/7 health care assistant). Another nurse commenting on a challenging situation (described in Vignette 4 above) stated *"I managed this situation because I have the skills and confidence to do so, a junior member of staff…it might have been a different outcome*" (S1/9 nurse). In order to provide good care for PWD it is essential to ensure there are sufficient numbers of staff in the department, but it is also important to consider the skills mix of the staff to ensure there is an appropriate balance of skill and seniority.

8.3.2 Use of specialist teams

The use and integration of specialist teams in ED is another important consideration for staffing. At both sites, specialist teams are available to support ED staff. At Site One, there is a specialist frailty interface team based in the ED to review patients over 65 who are screened for frailty at triage. This team is available from 8am to 8pm Monday to Friday. The trust also has a 'dementia team' consisting of two health care assistants who cover the entire trust. At Site Two, there is a frailty intervention team in the hospital who review patients in the ED by request. They work seven days a week, 8am to 4pm. The trust also has a ten person 'Dementia Team' consisting of care assistants, staff nurses and senior nurses, whom the ED can call to request assistance.

The majority of ED staff suggested that these specialist teams- both frailty and dementia- have been an overwhelmingly positive addition to the ED. They felt that teams have better training in geriatrics and a more appropriate skill set, which enables the teams to do rapid, and accurate, assessment of older people in the department. Additionally, these teams are external to ED staff numbers, and this makes it easier to provide one to one nursing care or support as they are empowered to focus on the PWD. One nurse said, "*There is a great palliative care team at* [the hospital]*, and a great frailty in-reach team. We could do with that being massively expanded! In a day they can see 13-14 patients*

and get 75% of them home. Its fantastic!" (S2/6 nurse). Another commented, *"the dementia support workers are doing a stalwart job. ED needs to call them in more often!"* (S1/11 nurse).

Vignette 5: Specialist support
A PWD was brought into the hospital from a care home via ambulance. The home suspected a UTI, which had caused increased confusion and agitation. The department was extremely busy, very noisy, and multiple patients were queuing in the hallways. On arrival to the department the patient was screaming and crying. The nursing staff attempted to get her settled, but the patient's agitation was making it difficult to communicate and the screaming caused distress to other patients. The nurse in charge called the dementia team to assist. A member of the team came with entertainment, which helped the patient get settled. With the support of the dementia worker, the ED team was able to undertake observations and carry out investigations to determine the cause of the increased confusion. There was very poor flow in the hospital that day so the patient had a long wait in the department for a bed on a medical ward. The dementia worker stayed with the patient for the duration of her stay in A&E and supported her to mobilize in the department to use the bathroom and to reduce agitation. The nurse in charge reflected that the support from this specialist was helpful as they had the correct skills to de-escalate the situation, succeed in undertaking investigations, and provide holistic care that would not otherwise have been possible with the number of patients they had in the department that day.

Source: Interview

Despite the benefits of these specialist teams, there are challenges that limit the effectiveness of these teams. A key complaint from ED staff is the hours that these specialist teams work do not align with the ED needs, as specialist services are largely concentrated on daytime hours and ED staff say they struggle most overnight. One commented "*in hours there is this 'bleep us anytime if you have a challenging issue, or you need advice or anything', but 2am on Friday night when* [ED] *is completed rammed, we still get patients with dementia and suddenly the support isn't there*" (S2/9- nurse). Another made the strong statement " *I don't see the benefit of the frailty team - consultant cover in ED is good during normal working hours and consultants are generally confident to decide who is safe to go home*." They further stated a specialist team is not very helpful "*unless they have some new skill set that allows them to magic an*

ambulance or convince a nursing home to take the patient back as those are really the barriers" (S2/4-consultant).

Another concern is that development of these specialist teams perpetuates the idea that dementia is a specialist area which lies outside the responsibility or remit of most ED staff. A frailty nurse summed up this sentiment saying "*Dementia is considered a specialist area- its not! Practically everyone has it!"* (S1/11-Nurse). Another specialist frailty nurse expressed a similar concern, sharing an example of a man with dementia who was kept in the department overnight to be seen by the frailty team in the morning despite being assessed as medically fit. They explained, *"He was assessed as medically fit, but because he had dementia, they didn't feel they had the skills, or the confidence to say actually you can go home now*", and went on to say, *"This was a normal injury! If it was you or I, we would have been sent home, but because he had dementia he was kept in"* (S2/12- nurse*).* She explained that they are starting to see this happen more frequently and stated *"They wait for the frailty team to come and do the assessment, but really…it's not rocket science! You pick up the phone and ask the carer 'how is it going"* (S2/12-nurse).

One potential explanation of these challenges is the relationship between the ED staff and the specialist staff. If the specialist staff are perceived as highly skilled outsiders, it can be harder for them to train ED staff and contribute to a change in culture. One specialist from Site One said, "*I'm not part of the ED staff team, I'm a guest in their area, so I'm there to support them"* (S1/13-nurse). This was notable in the observations at site one, where it was apparent that ED staff left patients who were visited by the frailty team for the duration of the assessment. In contrast, the ED staff at Site Two were more likely to stay while the frailty or dementia team interacted with the patient. According to the frailty team at Site Two this approach was agreed in advance with ED management and designed to help up-skill ED staff. She said "*when we come into ED, rather than working on our own, we work jointly with them so they share the skills and teach…we teach those skills live, while they are doing it so the staff member can then relate it back to the patient they are caring for*" (S2/2- frailty nurse).

Integrating the specialist staff into ED appeared to offer more opportunities for on the spot training and up skilling.

8.3.3 Leadership of senior staff and organisational culture

It became apparent the senior nursing staff play an important role in determining the organisational culture of the ED. The matrons and senior nurses who take on the 'nurse in charge' role dictate which activities are prioritized and what protocol deviations are acceptable. To a lesser extent, bed managers and tier one managers also play a role in establishing the environment of the ED- especially when there are pressures on hospital bed availability.

Staff nurses highlighted the importance of an *on-the-floor* presence of senior nurses as key to ensuring they felt supported, and able to access support, if required. Several staff made comments like "*an experienced nurse in charge, makes a huge difference- they need to be forward thinking, proactive, and confident. It's a lot about leadership"* (S2/5-Advanced nurse practitioner). In comparison, "*if we do have a leader who isn't present, who is spending lots of time in the office, or who is going on too many breaks it makes it a lot harder cause it makes you feel like you are there on your own"* (S2/5-Advanced nurse practitioner). This dynamic was visible during observations. For example, a nurse had a particularly challenging interaction with an abusive patient and left the bay muttering " *I am about to lose my shit*" if the patient doesn't "*cut it out*". The nurse in charge overheard and told the nurse to "*go take five and calm down*". The nurse tried to dismiss the concern saying they were just "*blowing off steam*" but the nurse in charge responded "*Its ok to be frustrated, that was tough- go get a cup of tea and come back fresh"* (OBS S1). The nurse in charge then covered that nurse's patients while the nurse stepped off the floor to get a cup of tea. In comparison, during another set of observations, there was no nurse in charge or matron in the area when a nurse had a challenging encounter with a patient that left the nurse in tears. The other staff nurses were sympathetic, but did not encourage the nurse to take a break and the nurse involved in the incident was observed to be crying on three other occasions within the four-hour observation period (OBS/S1).

While senior staff- such as nurses in charge or matrons- see the benefit of being at the sharp end of practice, they do not report having particular skills that enable them to manage PWD with behaviours that challenge. They simply feel having more experience enables them to cope with stress. One example given, by a nurse in charge was a PWD who was extremely distressed and aggressive in the resuscitation area, while the staff nurse in the area was also caring for two other patients. The nurse in charge felt they needed to do something to support their staff, but did not feel they had a particular skill or ability that would ensure a good outcome. They said *"it was a case of 'just have to get on and do something, because the poor nurse was a bit frazzled and trying to support these two poorly patients… and it's very difficult if you have got someone who is running riot in resus (*S2/8 nurse in charge). Another senior sister commented "*Some people don't do jobs because it's not their responsibility- but "there is no job to big, no job too small. If it needs to be done, do it!*" (S1/13 senior sister).

The senior nursing staff play an important role in establishing what practices are acceptable and whose care is prioritized. An example was given by a staff nurse who explained they went to their nurse in charge and proposed not to draw blood or do an ECG on a patient who had just arrived in the department. They told the nurse in charge "*sticking a needle into this lady who was already distressed wasn't a good idea*" (S2/6 -nurse) and the nurse in charge agreed, saying they would do an assessment based on observation and discussion rather than following 'intake protocol'. This ability to apply the policies flexibly to adapt to the needs of patients required a senior nurse who prioritizes person centered care.

Vignette 6: A team effort
Police brought a man to ED after an incident of domestic violence at home. He had a diagnosis of Lewy Bodies Dementia and was acting erratically and aggressively. The police attending the call spoke to his wife who requested that the man be assessed by clinicians rather than taken into custody. The police tried to de-escalate his distress before bringing him to ED. The nurse in charge and triage nurse who met them at the door recognised that this was a potentially precarious situation as the department was already full, understaffed, and the patient was mobile and aggressive. The triage nurse immediately called the

dementia team to come meet the patient, who came and stayed with him during initial assessment. The Dementia Team recommended the patient be moved out of the main ED area to the relative's waiting room in the observation ward as this was quieter, calmer, and a less medical environment. The dementia team called a mental health nurse. The teams took turns with the patient, which meant they were able to maintain his relatively calm status without causing undue strain for one staff member. The mental health nurse liaised with ED staff to request medications to stabilize his mood, which were administered in the family room. The ED nurse in charge communicated the situation to their counterpart at shift changeover, so no additional faces or disruption occurred. With this team approach, it was possible to keep the patient in ED until a suitable bed on a psychiatric ward was made available- preventing the patient's transmission to a potentially unsuitable ward.

Source: Interview

However, sometimes although the nurse in charge champions person centred care, the operational environment of the ED makes it difficult to provide such care. One nurse commented on the internal struggle they feel when they want to provide one to one care for a PWD and are compelled by biomedical necessity to prioritize the care of someone who is more acutely ill. They said, *"our priority is to maintain life, and the two* (providing holistic care & maintaining life*) just do not mix. At the end of the day, it's about patient safety, and we have to make sure both of those patients are safe" (*S2/6 -nurse*).* Another nurse commented that while it helps to have a senior nurse who encourages and supports the staff to provide holistic care, individuals are needed who are dedicated to that role. They commented *"You need set people to do that role, so your time isn't split between those high acuity patients elsewhere- you can just be set for the dementia patients- otherwise you are going to be distracted, no matter how much education you've got, you just won't have the time to sit and spend with those patients*" (S2/8-nurse).

Secondary to the support of senior nursing staff on the floor is the support of matrons or bed managers. While staff nurses did not frequently comment on this support, senior nursing staff- who reported looking to the matron or bed manager for assistance when the department became busy- regularly raised it. This dynamic was apparent on the day when observations took place while the department at Site Two was on 'black status'. On that day, the matron left her

office and set up a mobile desk at the nurses' station in order to be closer to the staff and see where assistance was required. During these observations the matron was seen providing comfort to a distressed family member, doing rapid teaching for a staff nurse, bringing a patient a urine collection bottle, making tea for staff and patients, and co-ordinating with hospital management to bring in additional staff. These tasks were undertaken in addition to her responsibility of liaising with a tier one bed manager to assist with patient flow. At one point during the observations the matron was overheard telling the bed manager that the situation was 'unsafe' in the department and one of the patients required a one to one support. At that point the bed manager came to the department and sat with the patient while continuing to co-ordinate the transfer of patients within the hospital from the bedside (OBS-S2). The support of the matrons and bed managers was commented on by a nurse in charge who felt the positive and close relationship they have with the tier one managers is key to the success of the department. They said, "*we'll often call up the site manager who is in charge of the whole hospital…. It's about forward thinking- we escalate early and communicate with each other" (*S2/9-nurse in charge*).* At Site Two, the responsiveness and understanding of the ED environment by management is perceived as a positive indicator of an open and supportive culture.

In contrast, if the senior management was perceived as failing to understand or react appropriately to the stresses of the ED, intervention from 'above' was unwelcome. The staff from Site One reported that requests for assistance typically went unanswered, and this had created a culture where asking for help was perceived to be useless. One commented "*some days we have escalated- I have escalated- 'we are struggling' and not much gets done about it… sometimes you'll get a bit of assistance, but quite a lot of the time its just 'try your best'*" (S1/7-nurse). This was commented on by the consultant from the site who noted "*There is a culture of tolerance of risk and underreporting, so the consultants and the rest of the nursing team have to try to turn that around* (S1/12). They further noted that culture change is a challenge

due to the stresses of managing the department, as they feel they often end up '*firefighting'* rather than being proactive. The consultant said:

> "*You do the work to get people to report, and then you end up with so many incidents being reported you can't keep on top of them, and week after week, we struggle to keep on top of the severe and moderate harm incidents, let alone learn the lessons that need to be learnt from the low [harm] and the near misses (S1/12 consultant).*

The consultant further explained that hospital management have contributed to this reluctance to report by implementing a '*sledgehammer*' mentality to problem solving in ED. They stated:

> "*The senior management can't understand the context- they think the solution to everything is to even more rigidly micromanage…you need to have a checklist, you need a protocol, completely missing the fact that what they need to sort out is access problems and flow! If we weren't having to juggle 20 balls we'd be much less likely to drop one now and again"* (S1/12, consultant).

It is clear that senior staff- both clinical and managerial- play an essential role in determining the culture of the ED. While a supportive and engaged management structure appears to increase staff confidence of and their willingness to escalate potential issues, management that is seen as non-responsive or micromanaging has a negative impact, especially on the likelihood of staff escalating issues.

8.3.4 Staff training

The training that ED staff receive- and its impact on the individual's preparedness to care for PWD - was explored in each of the interviews undertaken in this research. Two key types of training were highlighted; formal training in higher education settings, and informal (on the job) training, which staff gain throughout their career.

Generally, staff felt the formal training they received was not helpful in day-to-day practice as the training focused excessively on the biology of aging. Nursing staff and medical staff both report that dementia was touched on very briefly in their 'formal' education, and when it was discussed the focus was on the biomedical. One nurse who qualified over twenty years ago commented that they received no training on dementia during their course saying "*"in those days,*

you saw very few patients with dementia, now it seems like the whole hospital- at least 50% of patients have dementia" (S1/11- nurse*).* Another, who qualified in the last year, commented that while they had some training on dementia in their university course they felt the theoretical knowledge was difficult to translate into effective care. They said "*you got the basics I think- you learn more on the job really*" (S2/11 nurse). Another recently qualified nurse stated "*They teach you a bit around distractions techniques and things, but that can only give you an insight*" (S2/10- Nurse). Another commented "*we don't need to know more about the medical process of aging, we need to know how to talk to people with dementia, and how not to be afraid of interacting with a distressed patient!"* (S2/1-nurse). The physicians interviewed for this study also commented on the deficiencies in modern medical education saying;

> "*Cognitive impairment is creeping in there* [to ED education]*, but I wouldn't say it's front page, and I wouldn't say it's proportionate to the numbers that come through the doors with dementia…It's great that these chapters appear, but it's almost like a footnote...like oh, by the way, you'll see some patients that are a bit mad, they need to be cared for slightly differently*" (S1/12 consultant).

Another physician said:

> "*I can sedate you, I can give you an anaesthetic, I can reset your bones… I, but things that upset me and I find challenging are demented older people …or people with dementia who are not necessary older but have dementia…that you can't talk down, that you can't explain it's all going to be ok… how do you deescalate them?*" (S2/4-consultant).

These comments are reflective of the broader feeling amongst all staff that contemporary healthcare education is failing to capture the complexities of geriatric emergency medicine, and that the training provided does not provide the clinical skills required to effectively manage PWD, especially in the ED.

Staff felt they received better training and education effectively approaches to treating PWD while they were in practice. There was a consensus among staff that the best way to learn to interact with PWD is to learn from individuals who have developed skill through years of practice. Junior staff commented that they look to their senior nurse, nurse in charge, or

specialist teams for assistance when they have a patient they are struggling with. One commented, "*other than just exposure to it, you don't really know how to work with those patients*" and further suggested that learning on the job is the only way to build skill. This was echoed by a consultant who said, *"In ED training is mostly experiential- you can't work in ED for very long and not come across patients with dementia, so everyone is exposed to" (S1/12 consultant).* While senior staff acknowledge that they built their skill while 'on the job' very few of them reported that they actively teach the skills to younger members of staff. Some senior staff commented that if they saw a more junior member of staff struggling they would step in and offer assistance, however they did not feel approaches to facilitate communication or interaction was an essential clinical skill. Consequently, they reported these 'soft skills' are not typically considered core competencies in ED, and therefore they do not get taught to junior staff in a structured manner. One senior staff said *"I can't even remember where I learnt stuff- people now come to me to get support and stuff- but I don't actually know where I learnt it from*" (S2/3-nurse). Another reflected that while they felt their ability to develop rapport with family was key to their success they had never explicitly taught this approach to student nurses who worked under them in the department saying "*I guess I never thought about it really*" (S2/9).

The exception is senior specialists, such as dementia or frailty nurses, who work along side the ED staff who see actively up skilling ED nurses as a core part of their job. These specialist nurse expressed a high level of willingness to engage ED staff in training (S1/2, S1/11, S1/12, S2/2, S2/3, S2/12) but recognised that freeing staff up to attend training was a key barrier.

Overall, feedback from ED staff suggests they feel dementia training should be:

1) Annual (S1/2, S1/3, S1/4, S1/7, S1/9, S1/10, S1/11, S2/1, S2/3, S2/5, S2/6, S2/8, S2/10, S2/12)

2) Compulsory (S1/1, S1/2, S1/7, S1/10, S1/11, S2/1, S2/3, S2/8, S2/9, S2/12)

3) Stimulation based (S1/2, S1/2, S1/3, S1/4, S1/7, S1/9, S1/11, S2/1,S2/2 S2/3, S2/5, S2/6, S2/8, S2/9, S2/10, S2/12) and,

4) Focused on the day-to-day skills that enable staff to effectively interact with PWD. (S1/1, S1/2, S1/3, S1/4, S1/4, S1/7, S1/9, S1/11, S2/1, S2/1, S2/2 S2/3, S2/5, S2/6, S2/8, S2/9, S2/10, S2/12)

8.3.5 Emotional impact of caring

It is important to recognize the emotional impact of caring for PWD. Staff reported they are attempting to provide good care for patients with unique and resource intensive needs, in a time pressured, chaotic, and needs driven environment. In this research several respondents commented that the combination of circumstance and setting has a major impact on their emotional state, highlight two key impacts- anxiety and frustration. The anxiety is related to feeling unable to provide the care they would like due to a lack of skills or the patient having needs that are incongruent to the resources the ED has available. The frustration is associated with feeling unable to provide the standard of care they can and want to, due to resource constraints.

Staff reported that they are profoundly affected by patients who have poor experiences while under their care in ED, saying things like "*I close my eyes and I can still hear her screaming*" (S2/1-nurse) and "*he wouldn't stop saying 'stop hurting me' he was just so distressed…crying actual tears, it was awful*" (S2/6-nurse). Others commented that they carried these feelings of anxiety or powerlessness home at the end of their shifts saying "*you can't help but feeling bad when you get home and you think, I wish I could have done something differently*" (S1/9-nurse) and *"I go home and have nightmares about this place*" (S1/11-nurse). Some staff reported that they have had to 'detach from their emotional response' to prevent themselves from becoming overwhelmed or burnt out. One commented

> "*You get these 'little old dears, calling out in distress on the trollies in the corridor, and you sort of say, yes, yes Doris, you're alright, your daughter*

is coming, and then 2 minutes later they are calling out again, where am I, help me, help me, help me, and it's difficult. It's just sort of there in the background… and it's hard to hear and she just needs someone to hold her hand and make her feel safe" (S1/12 consultant).

They commented that it's an uncomfortable feeling to 'tune out' someone's suffering, but stated it's a situation they cannot change and have to carry on with their job.

Other staff responded with frustration about the working conditions that they felt prevent them from providing the care they are able and wanting to offer. One commented "*It's disheartening, having the skills, but not being supported to provide the type of care you are able too…it's why I want to leave nursing*" (S1/13 nurse). Another suggested they were thinking of leaving nursing as " *I could earn the same working at Aldi* [supermarket] *and it would be totally stress free*" (S1/1- nurse). Several respondents commented on the impact of the high stress environment and noted that ED nurses currently have a very rapid burnout period. One senior nurse reflected that when they started people chose ED because it was exciting and stayed for their entire career, but now they see "*people doing it for 2 maybe 3 years and then want to go work on a ward*". They attributed this to the pressures of ED, saying "*I've seen nurses break down, I've seen nurses go off sick with stress, because it's just constant. It's just really stressful*" (S1/9-nurse).

Vignette 7: Pressures of the job

A nurse who had participated in an interview earlier in the day was observed interacting with a PWD in the ED several hours after the data collection. In the unpressured interview environment the nurse had commented "*patients sometimes remove IV's, or pick at bandages, its just not a big deal, its not their fault. I don't let these things bother me as long as it doesn't cause harm*". Later that day one of their patients- a PWD- removed their IV line shortly before they were due to be transferred to a ward, getting blood all over the sheets. The department was extremely busy and several patients were waiting in the corridors for space in a bay to be assessed. When the nurse found the patients clothing and bedding covered in blood she sarcastically commented "*Oh brilliant mate, you've yanked out your line, that's exactly what I needed*" and then turned to a colleague and said "*guess your going to have to wait to get your patient into bed as mine has decided to be "helpful"- the porter will be delighted*". She then rolled her eyes. Immediately following this interaction she noticed I was standing at the nursing desk and commented, "*Whoops, I guess I didn't handle that as*

well as I said I would earlier today…". She then commented "*it's totally rammed in here and I haven't had lunch yet- I guess I am getting frustrated"*. She then changed the sheets on the bed and re-inserted the IV line before the patient was transferred out of the department

Source: Interview and observation.

This section has presented some of the key issues relating to staffing identified in this study. The impact of insufficient staff, or skills mix on that is not appropriate to the numbers or needs of patients was presented. The role of specialist teams within ED was discussed and the challenge of aligning working hours of specialists to periods of high stress was raised. The importance of senior nursing staff encouraging and facilitating the provision of holistic and person centered care was discussed as part of a broader discussion of organisational culture. The emotional impact of nursing PWD in ED was discussed highlighting dangers of burnout if anxiety and frustration are not recognised and addressed. Finally, this section discussed the education- both formal and informal- which ED staff receives, concluding that staff feel their formal education in dementia is misaligned with their practice based needs. Staff would prefer simulation training that focuses on the pragmatic skills that support staff when interacting with PWD day to day

8.4 Environment

This section discusses the ED physical environment and its effect on patient care. As noted in chapters two and three, the physical environment of ED has been identified as a key issue in both patient experience and safety. Whether environmental design facilitates or hinders good care is explored in particular detail- being reflective of the influence of human factors in the research process.

8.4.1 Lighting, acoustic's and layout

The importance of lighting, acoustics, and physical layout is apparent; as are the available "comforts" in the ED- such as food, drinks, seating and other facilities. Staff attitudes towards provision of 'comforts' in ED emerge, with a particular focus on the safety implications of conceptualising comfort as a clinical

necessity versus a pleasant addition to medical care for the older, confused patient.

Lights in the ED are typically left on 24 hours a day and designed to be bright enough to enable staff to do assessments and perform interventions safely. For PWD who are in the department overnight, the constant lighting can be a source of confusion, and it may prevent the individual from getting rest. When lights are left on overnight it is challenging to encourage PWD to rest. This issue was raised by multiple staff at both locations, with one asserting that it is a continual source of frustration: *"the lights don't go out at night!* (S1/7nurse). Another commented that having achieved sleep for a patient, they don't stay settled as the light makes them think they should be up: "*You get patients in, get them settled, then it comes night time…no lights off!"* (S2/10-senior nurse). In one example, a matron described how a PWD was admitted after a fall and was held overnight despite being declared medically fit as there was no transport home. Despite being encouraged to rest by staff several times, the man was continually getting out of bed, becoming confrontational and aggressive with patients and staff. His challenging behaviour was attributed to disorientation and over stimulation, as the patient was used to being in bed at that hour. They commented "*it was very noisy, there were patients all over the place, [in the] middle of the night, bright lights, noises, alarms, people talking, and I think that's probably the polar opposite to what you want*" (S2/11 matron)

Vignette 7: A wait in the corridor- *staff perspective*
An older man with dementia was brought to the hospital following an un-witnessed fall at his care home at approximately 10pm. When he arrived, the hospital was on 'black status' with no available beds, and had a queue of patients in the hallway who had arrived by ambulance but hadn't been assigned a dedicated treatment space. The man was placed on a trolley in a hallway queue and referred for investigations by the medics, which showed no injury. He was declared medically fit for discharge, but no transport was available to take him home and it was deemed unsafe to discharge him back to his care home in a taxi. He was calm on arrival, but became increasingly agitated the longer he spent queuing on the trolley. He refused to stay on the trolley despite being a high falls risk, he was fighting with the staff, spitting at people, and being aggressive with other patients. No specialist support was available because it was out of hours, and despite efforts by the nursing staff to de-escalate with supported mobilization, cups of tea, and conversation, his agitated behaviours

continued to escalate. The volume of patients in the department meant staff were unavailable to provide continual psychosocial care. The senior medical and nursing team decided it was best to sedate the patient for his safety, the safety of other patients, and staff in the department. After sedation, he slept for several hours before he was picked up by transport in the morning. The nurse in charge recalls being frustrated by the incident as they felt the patient should not have been left in ED overnight.

Source: Interview

One senior frailty nurse described the noise as "*incredible*" during the day, and "*not much better at night*" (S1/11- frailty nurse). Another commented, "*everything is toing and froing here, lots going on, all the time- I don't know if it's a distraction, or if it just makes things harder for the patient*" (S2/10- nurse). The patient and carer dyad who participated also commented on the noise in the department. The carer noted "*it was very noisy- even in resus…there was this one girl, she was quite upset I would say*…" (C2) and her partner added, " *oh she was just howling, it was such a racket, I just wanted to get some kip…but she was shouting something terrible*!" (P1). The issue of excessive noise in the department played a key role in an example shared by a frailty nurse who was called to intervene when a patient with dementia was labelled as 'attempting to abscond' from the ED. She indicated the ED staff wanted to sedate the patient for their own safety, but a brief discussion with the patient revealed that the distress was about excessive noise. The patient was moved to the quieter observations ward, where he quickly settled. This enabled staff to do their interventions and discharge him the same day.

Two further challenges for staff are 1) ensuring PWD who need observation are in an observable bay, and 2) providing nursing care in cramped or unsuitable spaces. Many PWD are considered to need additional observation due to their perceived 'high risk' status. To facilitate this additional supervision, staff attempt to place PWD in observable bays- an approach that is widely accepted and frequently used at both sites. One of the nurses commented "*we try to put people who are more at risk of confusion or falls or things like that into more visible places- so we wouldn't stick them at the end…we would keep them someplace more visible*" (S2/11- nurse). There are not always sufficient observable bays for the number of patients in the department, and this can lead

to PWD being placed in less visible areas. One nurse described the challenge of being responsible for five beds in a corner with no visibility from the nurses desk, saying when they work in this area they have to rely on the other patients to watch the PWD when staff leave to complete other tasks (S1/9- nurse). This nurse commented that positioning of the nurses desk, which forced them to turn their back on the patients every time they do charting or check the computers, is a problematic design feature.

Another challenge the nurses describe is the allocation of private rooms. In each ED, there are a small number of spaces that are designated for patients who need a separate environment because of their medical condition or their emotional state. Ideally these rooms could be used for PWD who need a quieter or calmer environment, but this can lead to challenges when patients with a bio-medical need arrive simultaneously. One senior nurse commented in those situations "*you are trying to balance the physical health of one of the patients and the psychological health of the other- should I give that private room to the person who is distressed, or to the person on chemotherapy*?" (S2/5- nurse).

Furthermore, ED's are now caring for more patients than they were initially designed to accommodate. This means staff are either care-giving in small bays or practicing in areas that were never designed to be clinical spaces. These space constraints can increase the stress. One commented "*If you are trying to help someone who is combative or stressed, and you are in a really tight space with them, you start feeling that stress as well, having curtains all around makes it hot- that makes you more stressed and more flustered*" (S2/5 nurse). Others commented on the challenges that come when they are trying to treat patients in corridors or spaces that were not designed to be clinical spaces. One nurse gave the example of needing to do an electrocardiogram during triage, which required moving the patient from the corridor to a space that was formerly a supplies closet (S1/1-nurse) and another gave an example of attempting to assisting patients to use a commode when they are waiting in a corridor (S2/7-nurse). Treating patients in corridors is common when the department is crowded and there is poor flow in the hospital. One of the nurses

commented "*being over capacity leads to working on the margins of safety, you are literally just trying to make sure the patient doesn't die on the trolley, and if you can, make sure they don't get a pressure sore…as for a bit of dignity? There is none*" (S2/1 nurse).

Another environmental challenge is the impact of the physical space on the carer. Several staff, and members of the care dyads, commented on the lack of space and equipment to facilitate the carer staying with the PWD during their time in the ED- most notably, the lack of availability of seating at the bedside. This is particularly challenging while patients are in the corridor. One carer reported that she had to leave her mother to '*hunt for a chair'* after being left standing in the corridor for a long time (C1), and another commented "***"****They gave us a chair in resus, but in the corridors, they are not, while you are standing waiting and you know you can stand and wait for a long, long time*" (C2). Both of these carers had mobility challenges, and found the time in the corridor especially hard, in part because they were physically uncomfortable while trying to support their relatives. The patient also commented on the lack of seating for his carer while they he was in the hospital saying: "*they left you standing a long time, didn't they love? It's the last thing you want to be worried about… I suppose I was quite comfortable- with the drugs you know- but I worried about her… she's got a bad back you see*" (P1).

Case 8: A wait in the corridor- *carer perspective*
Mrs. G. lives alone in the community. She has moderate dementia and a number of other co-morbid health conditions. Her five children and their partners all live in the local area and support her to remain in her own home. Recently, her health has been deteriorating and she has experienced a number of falls. In the past three months she has been admitted to the hospital twice.

The first time she was admitted to the hospital she had fallen at home and hit her head. Her daughter called for an ambulance and accompanied her mother to the hospital. When they arrived in the hospital the department was full and Mrs. G was placed in the corridor to await assessment.

Her daughter described her mother as "*battered and bruised and very frightened*" during her time in the corridor. She explained that as they waited, her mother's anxiety increased, and she became noticeably uncomfortable. Mrs. G began crying and calling out- a behaviour that her daughter knew was an

indication of her mother's anxiety. Despite having limited mobility, her daughter was unable to find a place to sit near her mother, and the nurses asked her not to move a chair into the hallway as it would make it hard to move beds through the corridor. Consequently, Mrs.G's daughter stood for a long time in the corridor trying to comfort her mother. The daughter felt the noise, bright lights, and constant movement of patients all increased Mrs G's discomfort.

Her daughter remarked "*there was a lot going on around her and it didn't seem as if she was being dealt with quick enough… but they were doing blood tests, so the waiting for the results to come through was very difficult*". When asked what might have made the experience easier for her and her mother, the daughter responded "*I think a nurse to be with her a bit more… again it is mainly reassurance that things are being done and what is being done*". The biggest frustration was "*not knowing what was happening, what to expect, or what was being tested for*". She indicated it would have been helpful to know "*What they are testing for and why*" as this would have removed some of the uncertainty, and stated "*Just to have that information would be helpful*".

Eventually Mrs G was assessed in the rapid triage area, where a senior physician reviewed her and determined that she should be sent to the medical assessment unit for additional tests. Her daughter described trying to interpret her mother's behaviour while in the triage area to the clinicians, indicating she was trying to explain that her mother wasn't deliberately being difficult or obtuse-she was just "*stressed and confused and anxious*".

The two most challenging elements of the experience for Mrs G and her family was the lack of information and the long wait in the corridor. The daughter described her anxiety over whether the hospital knew her mother was there, saying it would be helpful if someone said "*you have not been forgotten and you will be dealt with as soon as possible".* Additionally, Mrs G's daughter experienced stress as a caregiver because she could see that her mother's anxiety and fearfulness were increasing. It was a challenging situation to manage, and her daughter acknowledged that the only thing that could have made it better would be "*To be seen a bit quicker*". She further remarked "*it is the wait in the corridor….you are just in a long line and I have never experienced it myself being the patient though I can only imagine that it is not very nice being left on a trolley for quite a while*".

Source: Interview

8.4.2 Suitability of ED environment for people with dementia

Overall, the general consensus from ED staff is that the ED environment is not suited to the needs of PWD. Many of the respondents commented on the lack of suitability, saying things like "A*&E is the wrong place for them-*

completely the wrong place for them" (S1/3- dementia support worker) and "*its not an appropriate place for them, there is too much happening*" (S2/5- nurse). The same nurse who commented it was an inappropriate place expanded on their statement saying "*you don't want someone who is disorientated, who is anxious and confused walking around an A&E department- its not safe for them or others*" (S2/5- nurse). This was echoed by one of her colleagues who commented, "*A&E is not safe. It's not safe for an elderly person with confusion- it doesn't matter how much care you give them. It's NOT safe*" (S2/1 -nurse).

These challenges with the physical environment, and concerns about the safety and suitability have contributed to some staff believing there should be a separate ED or separate area specifically for PWD. Several of the respondents commented on the potential benefits of a separate unit, including the possibility of integrating dementia friendly design without affecting other patients. One commented:

> " *I was thinking today, we should have a separate elderly emergency department, in the same way that we have a separate paediatric emergency department... A lot of the risks, a lot of the things that happen to people with dementia when they are in ED, for example who wander, who get confused, and fall over and hurt themselves… the things that you have to do to address that, tend to make the department less good at looking after the bulk of the other patients. So to have a slightly different set up, to have an older peoples ED makes sense because we could have a different set up, different flooring, different lighting, different type faces, different clocks, all sorts while at the same time having an ordinary ED for the bulk of the patients."* – S1/12, Consultant

This sentiment was echoed by others, including an dementia specialist who commented "*ideally I would like to see a separate unit for those who are 75 and older, staffed by people who are confident and comfortable in interacting with older people, with the understanding that a stressed environment is not good for older people*". She further commented that a dementia friendly unit would need "*adapted environments to make sure there are quieter places, and an understanding that not every person with dementia will require the same resource to achieve desirable outcomes*" (S1/3-dementia team).

8.4.3 Accessibility of comforts

Another key element of the physical environment is access to comforts. For the purpose of this research, 'comforts' are defined as interventions or facilities that are primarily aimed at improving patients' wellbeing and experience of care. In some cases, such as access to entertainment or occupation, these comforts relate solely to patient experience, whereas others- such as access to food and drinks- also have clinical relevance. Access to these comforts in the ED can improve patient experience while also making it easier for staff to provide holistic care. Provision of these additional facilities and services is dependent on the organisation investing in the supplies required and the creation of an organisational culture that supports and encourages holistic care.

8.4.4 Occupation

One of the challenges that nurses describe in caring for PWD in the ED is the lack of meaningful activity for patient to engage with while they wait. They report boredom is a major issue for many patients, and this can lead to behaviours that challenge such as walking around the department or becoming agitated. Several of the nurses commented that they recognised these behaviours as boredom saying ""*They can stay up to 20 in hours in A&E, having something just to keep them distracted would be good*" and "*relieving boredom, frees up the nurses to do their job*" (S1/9-nurse). During the observations, two nurses could be heard discussing a patient who was walking around the department talking to people saying "*she's bored isn't she, bless her" (OBS-S1*).

Some of the respondents described scenarios where they were able to divert patients whose behaviours were becoming challenging by engaging them in activities. In one example, a woman who had been a laundress was given stacks of linens to fold (S1/9-nurse) and another nurse supplied paper and pencils to a man who had been an architect and asked him to design a new hospital ward (S1/7-nurse). Another described a scenario when she had a patient who was formerly a hospital cleaner saying " *…she used to get up and try to clean the department. She would get so upset when they kept trying to put her back into bed, so I just said 'let her clean!" For infection control I had to go*

behind her and redo things… but she's happy, leave her!...it was cleaned beautifully Literally the nicest I've ever seen" (S2/3 -nurse).

When staff were asked what would make it easier to provide good care to PWD in the ED the most frequently cited items were items to entertain or distract such as picture books, magazines, fiddlemitts, sensory games, newspapers, and/or calming stimulation such as imitation fish tanks. Staff members with a particular interest in dementia reported purchasing items with their own money or bringing items from home to supplement the ED supplies, but said this was unsustainable in the long term as items continually were taken from ED (S2/3 and S1/13). The full 'wishlist' of items, supplies, and adaptations identified by staff as potentially beneficial to provision of good care can be found in appendix twenty four.

8.4.5 Food and drink

Access to appropriate foods and drinks- both hot and cold- was a core theme. Staff at both sites described the importance of ensuring patients are well hydrated and have access to food. Hot drinks in particular are seen as both a means of keeping patients hydrated as well as providing comfort and orientation. One nurse said "*if you understand nothing else around you in your environment, you can still understand a cup of tea"* (S2/11- nurse). Another commented: "*a cup of tea goes a long way*! (S1/14- health care assistant) and this sentiment was echoed by a dementia nurse specialist who stated "*tea is always good- tea is the answer to everything*" (S2/14).

Vignette 9: Adapt the environment and provide entertainment
A lady with advanced dementia was brought by ambulance to ED after a fall. She was extremely distressed on arrival- insisting that the ambulance crew had picked up the wrong person. She was becoming increasingly aggressive with staff, swinging her walking stick at them. She was put into a separate room in an attempt to de-escalate the situation, but her agitation increased continually. One of the nurses-who up to this point had not been involved in her care-moved the bed out of a cubicle, replacing it with two comfortable chairs and a table and invited the patient to come join her in the 'lounge' for a cup of tea and to watch TV. This new environment helped settled the patient and once she was calmer it was possible to carry out investigations that determined she was medically fit to be discharged. It was after hours and transport was not available, but her son offered to come pick her up. She spent several hours in the department while

her son finished his shift at work. Despite the delay she remained calm with 1-1 support from the nurse whom she had good rapport with. She was encouraged to mobilize in the department, accompanying the doctor as they walked around, and was invited to sit at the desk with the nurse in charge. The nurse who intervened was able to swap responsibilities with other nurses on shift to enable her to focus on the distressed patient. This is an example of care which the nurse was particularly proud of as the patient came in screaming and terrified, but left giving hugs and kisses to all the members of staff.

Source: interview

Despite the recognised value in keeping patients hydrated and fed in the department, the importance placed on providing food and drink appears to be tied to the culture of the unit. At Site Two, the provision of hot drinks was seen as an essential part of providing care in ED with staff taking great pride in the fact they provide tea and food even when its busy. They said "*even if we are massively busy, we are quite good here with tea or drinks or food or things like that*" (S2/3-nurse) and "*I'm always making people drinks and sandwiches, because I don't feel I would be assessing them fairly…if they haven't had food or drink they aren't going to be feeling very mobile, or very good*" (S2/2-frailty nurse). This ethos was embedded in the culture of the department- with senior nursing staff offering to cover staff nurses patients while the staff nurses go to make tea and get food for the patients. During one period of observation at Site Two, an ED consultant was observed asking several patients if they would like anything to drink as he was headed to the kitchen to get himself a coffee (OBS/S2). On another occasion the matron was observed bringing a cup of tea to a family member who was standing outside the resuscitation room crying. The value placed on ensuring patients and carers have access to food and hot drinks is summarized by a senior dementia specialist who noted that "*taking 5 minutes to step off the floor to make a cup of tea means that maybe you'll prevent something later*" and "*that [cup of tea] may then help your patient walk out of the place!"(*S2/12).

In contrast, at Site One the provision of food and drinks was perceived as something that was nice to do, but only when the department was not busy. This was commented on by an older person's specialist nurse who works in the ED who said *"I think its important for staff to know basic things, like a cup of tea and*

coffee or food is really an essential part of an older persons care, and unfortunately it sometimes can be seen as quite low down- when you are busy in the department, who is going to think of making someone a hot drink?" (S1/3-nurse). Another nurse commented *"I would love to make someone a cup of tea, but my job is to keep people alive…. If we want to make a cup of tea for them, I've got to go out to the kitchen. To get a sandwich?* (trailed off*)..... its only possible when you have less patients and people with less medical needs*" (S1/9-nurse).

This can lead to patients- and carers- going for several hours without food or drinks being offered to them. It is especially apparent when the department is busy and the HCA's have been pulled forward to the front door to assist with triaging, which takes them away from the majors area where they would usually be assisting with food, fluids and personal care. One of the nurses commented that when the HCA's get 'pulled forward' she has seen scenarios where *" there are people who don't get a drink for 10 hours*" (S1/11 nurse). Another nurse commented that while she worked at Site One she was distressed to find "*patients who haven't eaten for 12 hours straight who are diabetic*" commenting that in those cases the care is "*negligible!"* (S2/12).

8.5 External factors

This section briefly addresses some of the external factors that are influencing the quality and safety of care that is provided in ED's for PWD.

It is important to note that these are complex, multifaceted issues with wide ranging implications across the health system. While it is felt that it would not be possible to properly address the issue of dementia in ED's without identifying these external factors, a detailed analysis of these factors lay outside the remit of this project.

This section consequently considers,

1) Impact of government austerity policies on staff levels and resource availability
2) Access to care in the community- including GP appointments, palliative care, and social care and support.

3) Nursing homes

8.5.1 Austerity

Several of the respondents commented on the challenges that have arisen as a result of austerity driven lack of investment. These challenges include 1) insufficient numbers of staff to care for the number of patients, 2) failures to recruit and retain new staff- especially nurses, and 3) lack of funding for social care causing serious delays in discharge which creates congestion in the ED when there are no beds available in the hospital.

Austerity measures cause significant stress for many staff, and in some cases it has led to disillusionment or a desire to leave the caring professions. One commented, *"You should go home at night thinking I did a good job, not thinking about what you haven't done, what you couldn't do, what you can't do"* (S1/11-nurse*).* Another commented, *"Its just very stressful, nowhere for patients to go, no beds to move onto* (S2/8 nurse) and another said, "*everything is in a bit of a state really-isn't it*" (OBS-S1). For some, the austerity measures are perceived as a means of artificially causing the system to fail for political reasons. When asked during the observations what might make a difference in the ED, one of the nurses responded, "*more doctors, more nurses, more EMA's, better pay…we are literally falling apart here*" (OBS-S1). One of their colleagues followed this up by saying *"they are trying to break us, just trying to make us fail so they can privatise" (OBS-S1*).

8.5.2 Access to community care

Poor access to services in the community was a frequently cited external factor which influences the ability of staff in ED to provide good and safe care for PWD. As noted above in the patient characteristics section, those with lower acuity receive less priority in ED, but are nevertheless directed to the department because of poor availability of appointments with general practitioners (GP's). In particular, the lack of access to GP appointments for people living in nursing homes was commented on. One of the physicians commented, "*They sometimes arrive in an ambulance, and the ambulance crew*

says 'well they were waiting on a GP appointment, but no one turned up, so they called an ambulance, and then they just sort of get dumped on us'" (S2/4-physician). When it is not possible to be seen promptly by a GP, nursing homes and families turn to ED as it is seen as a way of getting rapid diagnosis and access to care. Unfortunately, this pattern is also reflected in general attendances, not just those living with dementia, and the increased demand for ED services is causing long waits and overcrowding.

Delayed access to care and support in the community is another commonly cited issue that brings PWD to ED. Several respondents commented on how frequently they see patients who are designated as '*waiting for assessment'* or on a wait list for review and services. For some patients and families, the long delays to accessing services results in crisis that results in a visit to ED. One respondent commented on a case they had been involved in, stating ""*They had asked for help, but I don't think anything was happening as quickly as it needed to…*" (S1/12-consultant). Another commented on the impact of delayed access to social services, stating "*There isn't enough, and what there is [is] spread so thin, people are being brought to A&E because they aren't getting the care they need. That's not social services fault, it's just spread too thin*" (S1/1- nurse).

Another theme that emerged in discussion of access to services in the community was the challenge of getting community palliative care for PWD. The consensus from staff is that ED is a wholly inappropriate place for someone who requires palliative care. One nurse commented "*those at the end stages of the disease, those where the swallow has gone- they are the ones who really shouldn't sit in ED*". One major challenge for ED is the inability to determine which patients should receive palliative care. Unless death is considered imminent- i.e. within hours- the ED staff must refer to the palliative care or inpatient teams and provide intervention in the interim. One nurse commented, sometimes "I *know its not the right thing for this patient, but in the interim period we have to be seen to be doing something until the medics withdraw that treatment*" (S2/6-nurse).

Vignette 11: Palliative care in the ED

An older man was brought to ED from his care home with end stage heart failure. He did not have any "do not attempt Cardio-pulmonary resuscitation" (DNACPR) consent forms with him or an advanced care plans in place. He was extremely distressed on arrival, crying and struggling to breathe. He was transferred directly to the resuscitation area and the nurse told she needed to start IV's, insert a catheter, and get him prepped for bi-level positive airway pressure (BiPap). While she carried out these procedures, he cried and shouted out "*they are beating me black and blue- they are torturing me*". He was sent for a chest x-ray that revealed a previously broken shoulder that had never been reset properly. The nurse called his care home and discovered the man had been a prisoner of war during World War Two, was in chronic pain from the shoulder, and experienced distressing flashbacks of his captivity during the war when he was in pain or uncomfortable. With this knowledge, the nurse went back to the consultant and stated that starting the patient on BiPap was not in his best interest due to his considerable distress and terminal condition. The consultant argued that ED staff couldn't make palliative care decisions without an advanced care plan in place as this could open the hospital to claims of malpractice or neglect. Eventually the consultant agreed to provide additional pain relief and oxygen via face- mask rather than BiPap until the palliative care team could assess the patient. The nurse described the several hours she cared for him in ED while waiting for the palliative care team as '*agonizing*'. She reflected that the patient could be easily settled with a hug or gentle stroking of his head, but she did not have the capacity to provide 1-1 care in resuscitation, as there were two other patients. She further commented "…*its not comfortable at all, its not what I got into this job for, and I feel more and more that we are making these decisions against someone's wellbeing, but clinically on paper we have to do the right thing"* After several hours a member of staff from the nursing home came to be with him after her shift at the home ended. The palliative care team came to assess him and determined he should be moved to the palliative care wing. He was moved and died a few hours later.

Others commented that they had been instructed to move patients while they were actively dying to prevent admissions breaches or to make space for other patients. One stated "*…if someone arrives in A&E and it's deemed that they are end of life, we try to tuck them into a side room. Try to give the family some time and space to say goodbye- but they are still subject to the 4 hour and 12 hour targets- you can end up moving someone in the midst of actively dying"* (S1/9- Nurse). This not only causes distress for the families, but also for the staff who feel they are not being enabled to care for their patients in a dignified and respectful manner.

Several nursing staff commented that it is challenging to keep patients in the community at end of life because families don't have access to palliative care nurses. The families then call for an ambulance when their relative displays distressing symptoms-such as changes in breathing which are perceived as potentially reversible. Once the ambulance arrives, they have a duty of care and frequently end up conveying people to hospital even when they know it is not in the patient or families best interest. One of the frailty nurses commented, "*I wonder- if those ambulance crews had someone in the community they could contact, would they be conveying so many people to hospital?"* (S2/2- frailty nurse).

Some staff also felt nursing home policies are responsible for the increasing numbers of PWD arriving in ED at the end of life. They feel some nursing homes do not want to take responsibility for co-ordinating and delivering palliative care. One commented "…it's like *it's not ok for old people to die in a nursing home anymore….but really, isn't that sort of what its there for*? They further commented, " if [the home] thinks [the patient] *might die - they worry it reflects sub standard care*" and so they send the patient to ED so they are seen to have reacted appropriately to 'deterioration' (S2/6 physician).

8.5.3 Nursing homes

The most frequently cited frustration of ED staff with nursing homes is protocols, which mandate transfer to ED- for example 'un-witnessed fall' or ' fall with potential head injury by someone taking anti-coagulants'. Regardless of how these patients may be presenting clinically, the protocol dictates that they must be immediately brought to ED for assessment. One nurse commented "*a lot of times someone has a fall in the nursing home, and they get sent in because that is the protocol, but then you have got someone with severe dementia in ED, and is there an element of… did they need to be here*?" (S2/10- nurse). Unfortunately, many homes do not have the resources to send a carer with the patient, which leaves the patient alone in the department. This is particularly challenging when the patient is asymptomatic and presenting as 'physically well', as they are given lower triage priority.

In other cases ED staff believe that the nurses and care workers who work in nursing homes should be providing more, or better care in the home. Some ED staff believe that on occasion the standards of care in homes are so poor it is negligent. Staff are frustrated to see patients arriving in ED with urinary tract infections and bedsores which they feel could have been prevented with better care. One commented, "*Some of them are appalling the way they are run- we see instances of neglect and abuse*." (S1/1-nurse) and another said "*its frustrating...if you are working in a nursing home- then nurse!"* (S2/6 -Nurse).

Vignette 12:Care staff going above and beyond.
A gentleman was sent to the hospital following a fall at his dementia specialist care home. The care home sent him to hospital in a private vehicle with a carer whom he was familiar with. The carer brought a full copy of his medical history and current medications as well as his "This is me" form. The carer stayed with the gentleman throughout his time in the department keeping him relaxed and oriented despite it being a busy day in the department. Later that afternoon, another patient from the same home was also sent to A&E with an un-witnessed fall. The carer from the home requested that they be placed near each other so she could continue to support both patients and offer assistance to the nurses providing medical care. She informed the department of her intent to stay with the patients until they were released to ensure their discharges were not complicated by a lack of transport. When both patients were released at 10pm, she put them both into a private vehicle and took them home. This good outcome was largely made possible by the presence of a member of staff from the nursing home, as their presence meant the hospital staff were able to focus on providing expedient medical care and assessment while remaining confident that the holistic needs of the patient were being met. The patients both remained calm and orientated throughout their stay despite it being an unusually busy and loud day in the department. Having rapid access to accurate medical and medication history made it easier for hospital staff to make informed decisions. The willingness of the carer to stay for over 9 hours in the department to ensure both patients could get home and into their own beds was reported to the care home and commended by the hospital staff.

Source: Interview

Finally, the ED staff reported frustration that the nursing homes do not send information with the patient when are transported to ED. They feel it makes their jobs harder, and represents a failing of care on the part of the nursing homes. One said " *without information it's harder to assess things like confusion- is it normal or the result of the fall? We need to know if the behaviour is normal, because if it is, you just get on with it, but if it isn't we need to look into that*

further!" (S2/1-nurse). For ED staff, the homes that are considered the best are those who ensure information is communicated effectively, and where staff are able to provide personal information in addition to notes.

8.6 Reflexive note

During the observations, I intervened in three separate occasions when intervention was judged to be in the best interests of the patient. In these scenario's "intervention' is defined as identification of a potentially dangerous scenarios to a member of ED staff who had previously been unaware of the potential risk. In two cases this involved patients with neck of femur fractures attempting to mobilize from a bed without assistance, and in a third case a patient was standing on their bed trying to reach for a curtain railing. In each of these cases, the nursing staff of the department had been significantly depleted by an unfilled rota and nurses being 'off the floor' doing transfers. From my position at the nurses station I had the luxury of uninterrupted observation, whereas the nurses were occupied with multiple tasks including patient care and electronic charting. In each instance, I gently alerted a nearby nurse to the unfolding scenario by saying "I am concerned about the patient in bed….". In all three cases this identification resulted in a rapid response from the nurse to reduce the immediate risk to the patient. On two occasions the nurse offered their thanks saying " *thank god we had an extra set of eyes- that could have been a disaster*" and " *cheers for letting me know*". On the third occasion the nurse seemed annoyed with the intervention and was overheard later telling the nurse in charge "*everyone's a critic, but nothing ever changes*" which I perceived as her reaction to my earlier intervention.

As a researcher, it was extremely difficult to determine where, and when I should intervene, as the moral imperative to prevent harm befalling another person had to be balanced with the research goals of identifying how ED staff recognise and react to safety risks for older patients with cognitive impairments. In several other cases, I decided not to intervene when I identified potentially risky behaviours that had not yet been identified by nursing staff- such as

attempting to remove IV lines- as I deemed these less of an immediate threat to safety and less likely to cause lasting harm.

Trying to navigate the balance of being an objective observer, while also developing and maintaining a productive and professional relationship with the ED staff was at times a challenge. When I felt the relationship with staff was strained or that I was unwelcome this had an impact on the experience of observation. I used my personal reflective journal that I completed at the end of each session as a pre-amble to my observation notes so I could revisit my notes with a critical understanding of my emotional state at the time.

One of the major challenges I faced during the interviews was the death of my grandfather- who had been living with dementia- half way through the data collection. His death came only seven months after the passing of my grandmother- who also lived with dementia. Unlike her passing in May, which followed an extended illness, my Grandfathers death was completely unforeseen, and I mourned the dual losses very deeply. To enable me to attend with minimal disruption to my studies, the funeral was delayed for over a month, to a time I was already scheduled to be home attending a conference. While the intention was to allow me to carry on with my research, the interim period was extremely challenging.

Prior to his death, I felt I had successfully maintained a professional separation between my experiences as a former carer and family member with my role as a researcher. After his death, I found myself becoming very emotional during certain interviews- in particular if the attitude of the respondent was misaligned with person centred philosophies. I recall one interview where the respondent referred to people with dementia as "*like dogs- not able to understand what's going on*". While I managed to complete the interview, I left the site and cried for an extended period before returning. Shortly after, a participant became upset and tearful during their interview, and as per protocol- I turned off the recording device to have an informal conversation with her. While I felt I managed to maintain my professional composure and act as a support to them during their period of distress, I found the experience extremely

emotionally draining. After these two experiences, I was concerned about the ethical implications of carrying on with additional interviews- in particular, interviews with family carers and people with dementia. I was concerned that there was a risk of my emotional state compromising the integrity of the data. In qualitative (ethnographic) research this is a recognized risk to quality of data.

In reflecting on the impact this may have had on the data collection, I believe the structured nature of the interviewing framework minimized the risk that data collection was negatively impacted, however, the emotional labour which was required to maintain the relationship with participants was extremely draining and continuing was having a significant negative impact on my mental health.

I spoke to my supervisors about my concerns, and they encouraged me to take a short break from data collection and do some transcription and preliminary analysis. While doing this preliminary analysis, I became confident I had sufficient data to answer the research questions without carrying out additional interviews. It was a difficult decision to change the sampling framework that was planned, but ultimately I believe it was the best decision both for the research, and for my well-being.

Co-design of consensus "Dementia Friendly Emergency Department statements

9.1 Introduction and purpose

This chapter presents the co-design process that was used to develop a set of consensus statements on what constitutes "Dementia Friendly Emergency Departments". These statements are a major research output from this project. This is an integrated methods and results chapter, as this phase of research was considerably smaller than the others. The value of consulting experts by experience in research was clearly demonstrated during the co-design process used in Phase One. The researcher felt it was essential to involve experts by experience in interpreting and disseminating the key messages from the research and therefore included this second round of co-design work in Phase Three. The academic and theoretical rationale for the use of co-design will not be revisited as this has been extensively covered in the methodology and methods chapters when discussing the co-design process used for Phase One.

9.1.1 Aim

The aim of this phase was two fold; firstly to engage in participant validation of the findings, and secondly to develop a co-designed statement that presented a model of what 'dementia friendly emergency departments' are. To achieve these aims the researcher arranged a number of opportunities for patient and stakeholder participants to interact with the findings. These opportunities were; a full day, patient and public involvement (PPI) event hosted at the University of Bradford and a community meeting at a day centre for people living with dementia.

9.2 Methods

This phase of the research had two distinct stages.

Stage one: Validation of the findings and initial co-design process.

Stage two: Validation of the 'Dementia Friendly Emergency Department statements'

9.2.1 Recruitment

In April 2018 the stage one event was promoted using multiple approaches, including:

- Targeted invitations to individuals who had participated in previous phases of the research and expressed an interest in contributing further to the project
- Promotion via twitter on the researcher's personal twitter account, with support from the University of Bradford social media team to maximize reach. (See appendix twenty five for examples of the poster shared)
- Posting on the University of Bradford Dementia Studies Facebook page
- An email invitation to participate sent to the 'experts by experience' panel at the University of Bradford, and
- An email invitation to a community group the researcher was scheduled to meet with

9.2.2 Participants

Stage one involved three former carers and one current carer. Two people living with dementia were scheduled to attend, but due to personal circumstance could not attend in person on the day.

The participants in this co-design workshop were;

Participant 1: A palliative care nurse and former carer for a family member living with dementia

Participant 2: A community services manager and former carer for a family member living with dementia

Participant 3: A retired HR professional and carer for a family member living with dementia

Participant 4: An expert on south Asian carers and former carer for a family member with dementia

Participant 5: *Participated via e-mail*. Living in the community with vascular dementia and a member of the patient led 'Assessments of Care Environments' project at local Care Trust.

Participant 6: *Participated via email.* Retired NHS staff development officer. Currently living in the community with dementia.

In addition to the participants who attended the full day workshop, and actively participated in the co-design process (stage one) a number of additional participants contributed to the validation process in stage two. These additional participants attended a meeting at a day centre for people with dementia in June and engaged with the drafted statements during the meeting.

Participant 7: Retired maintenance worker. Leader of the Dementia Peer Coalition at the care home they live in. Currently living with dementia.

Participant 8: Retired University provost. Currently living with dementia and resident in a care home.

Participant 9: Retired astrophysics engineer. Currently living with dementia and resident in the community with their partner.

Participant 10: Director of day services in a care home, staff liaison for the dementia peer coalition.

9.3 Process

9.3.1 Stage one:

At the start of the day the participants who attended in person were invited to share their experiences of caring for a PWD and any visits to ED they experienced during their caring experience. The researcher shared written

feedback from the people living with dementia about their previous experiences of ED, having gained prior consent to do so from the participants. The researcher then facilitated a process of group goal setting for the day to create a shared purpose that was equally owned by each member of the group. Unfortunately the goal setting could not include the individuals who contributed via e-mail, as the goal setting was discussion based and iterative. It was not possible to get feedback in real-time from the remote participants. The researcher then presented the data that had been collected during both phases of the research. Due to the limited number of participants, the day was informal in tone, and participants were encouraged to share their reactions and thoughts during the presentation. This discussion-based format enabled dialogue to emerge authentically, and was intended to counteract hierarchies of importance, which can emerge if highly structured or rigidly controlled formats are utilized by researcher to direct the event.

After a break for lunch, participants were invited to share their thoughts on what makes an ED dementia friendly based on their experiences and the data they had been presented in the morning. The researcher facilitated discussion and made notes. The participants identified the following as core components of a dementia friendly emergency department

- Approach to care
- Knowledge and understanding
- Language
- Information sharing
- Physical environment, and
- Recognition of the carer needs

After agreeing these categories, each participant wrote their thoughts about what specific content should be in each category and shared it with the group. While the participants who were physically at the university completed this task, the researcher emailed the PWD who could not attend in person for their input. Once the participants had an opportunity to write out their thoughts, the content was shared with the group.

There was considerable consistency in the responses, and the group settled any disagreements by discussion to reach consensus before continuing. The biggest concern was how best to integrate carers' needs in the model - as it was recognised that not all people with dementia attend ED with a carer and the focus of the statements is primarily about the patient. The discussion centered around the importance of ensuring carers needs are integrated into the model in a way that recognized the potential for carer needs to be divergent from patient needs. Furthermore, the importance of recognising carer needs as distinct was raised. After discussion, it was agreed that carer needs would be included in the main model, but would be separated by indicating "If a person with dementia attends with a carer…" at the start of the section on carers' needs in recognition that not all PWD will attend with a carer. Additionally, the group felt separate sections would maintain a clear distinction between the needs and experiences of the patient and the carer.

The day after the PPI event, the researcher collated the written feedback from participants - including the PWD who could not attend in person- and the notes from the day. The researcher then consolidated the content into a provisional set of statements. These statements were circulated to participants of stage one (participants one through six) for their feedback. Two participants responded with minor edits, and the others agreed the statements were an accurate representation of their thoughts on what a dementia friendly emergency department is.

9.3.2 Stage two

Three weeks after the model was developed, the researcher was invited to visit a community group of people living with dementia who had expressed an interest in becoming more active in research. This group was chaired by a person living with dementia, and included several residents of a nearby care home as well as individuals living in the community. The group meets monthly, and has a membership of between seven and eleven people with dementia who participate in the peer-to-peer support program. The researcher asked if it

would be possible to share the drafted model during the meeting, in order to elicit their feedback and reactions.

After introductions, the researcher was invited to speak. They opened their presentation by explaining the model was a drafted output from a broader research project, and that they would value the thoughts of the group on the content. The group- which on this day included participants seven through ten- were all given a printed copy of the model, and the researcher read the statements out loud. Each statement was discussed in turn, giving the group an opportunity to share their reaction to the item. The feedback from the participants was largely positive. In particular the group commented that they appreciated the specificity of the model -which focused on actions rather than policy. For example, they felt it was powerful to state staff use their training to "provide care that is person centered and ensures their approach is suitable to the needs of the individual" rather than simply stating staff should have training in dementia. Overall, they concurred that the model was an accurate reflection of their perception of a dementia friendly ED.

The group proposed one addition to the model. They felt the statement on compassion and dignity should also include the word respect. The group indicated they felt respect and dignity are separate, but equally important concepts and should receive equal, explicit, mention in the opening statement. After the meeting, the updated model with respect added was re-circulated to the original six members of the co-design team and they unanimously offered their endorsement of the updated model that included the term respect.

9.4 Output

The following is the model that was co-designed as an output of this research.

In a Dementia Friendly Emergency Department;

- People with dementia are treated with compassion, dignity and respect.
- Staff members have training in dementia, which they use to provide care that is person centered. Staff adapt their approach to ensure it is suitable to the needs and abilities of the individual
- The impact of dementia on cognitive ability (*such as memory and processing*) and behaviour is understood. Adjustments are made to support the person with dementia.
- Staff uses appropriate language when interacting with people with dementia and their carers.
    - Language that is non-stigmatizing
    - Language that is easy to understand
- Information about care processes, diagnosis, and future plans are communicated to the patient and carer accurately and in a timely manner
- The physical space is safe and comfortable for people with dementia
    - There is a quiet or quieter space available
    - There are facilities which enable and support a carer to stay comfortably
    - There is easy access to food and drinks
- If the person with dementia attends with a carer;
    - The experience and expertise of the carer is recognised and acknowledged.
    - Staff commit to creating partnerships of care where the carer is a respected member of the care team and supported to be involved in ways they are comfortable with.
    - The potential emotional strain of caring is recognised, and the needs of the carer are considered as part of the care planning process

The lay language of these statements reflects the direct contributions of the co-designers- lending credence to the ‘stamp of authenticity’. The shift towards genuine co-production of research outputs demands shared ownership of the content and presentation of findings, as it inevitably involves power redistribution that challenges traditional hierarchies (Bovaird, 2016). Therefore, shifting towards authentic collaboration- rather than engaging in tokenistic gestures such as consulting or informing (Arnstein, 1969)- can change the nature or presentation of research outputs. However, authentic co-design also improves research outputs by increasing the breadth of sources from which content is drawn, and- in this research- enabling those living with dementia to contribute to the broader discourse on priority setting and health systems reform with active and autonomous voices.

Discussion

10.1 Introduction and purpose

This project provides the first comprehensive investigation into the experiences of people with dementia (PWD), their carers, and the staff who provide care in emergency departments (ED) in the UK. This is novel work for a number of reasons. The mixed methods, iterative, design allows a holistic evaluation of the current experiences of the key parties involved in receiving and providing care in ED. Second, PWD and their carers have determined the research priorities and co-designed both the first phase of this work and contributed to interpreting key conclusions. Third, a systematic approach has been taken to identify the contributory factors, which act as barriers and facilitators to effective care for a population of patients that continues to grow and as such, represents a considerable strain to health services.

An earlier study by Parke et al (2013) investigated the ED care processes and experiences from the perspective of PWD and their carers, and although their sample included PWD, carers, and nurses in Canada, the sample size was small (N=10) and the research was descriptive rather than explanatory. This project is considerably larger in both size, and scope, utilizing both qualitative and quantitative methods to draw conclusions from the data, which have been deductively and inductively derived. Fylan (2015) previously used the Yorkshire Contributory Factors Framework (YCFF) to analyze medication errors, but to the knowledge of the researcher, this approach has not be used to assess care of PWD or ED care despite its value as a human factors approach to assessing complex dynamics of care.

It is now well recognized that PWD experience avoidable harm or other poor experiences of care while in the ED with considerable frequency. The physical structures, care processes , and organizational cultures of ED all contribute to increased risk in this setting. The core premise of a human factors approach, such as the one utilized here, is that by increasing understanding of interactions between (fallible) humans and other elements of the ‘system’ we

can engineer or redesign our systems to optimize performance and minimize risk (Carayon, Xie, & Kianfar, 2014; Dekker, 2011). Assuming the intention of providing healthcare is to protect and enhance a patients wellbeing, and using Reason's (1990) definition of error- “the failure of a planned action to be completed as intended” (Pg 9), we can conclude that some form of ‘error’ is occurring in emergency care for PWD which is leading to these poor outcomes. In order to make suggestions to improve the system, build layers of protection, and reduce probability of human error, it was first essential to define the specific errors which are occurring. Rasmussen & Jensen (1974) propose a three-layer taxonomy of error, proposing errors can be skill based, knowledge based, or rule based. Preventing, or reducing error is contingent on identification of the type of error, and providing effective and appropriate institutional response.

It was hypothesized at the outset of the project that there were several potential explanations for the poor outcomes of care PWD were experiencing; 1) ED staff lacking sufficient knowledge of the priorities of care for PWD, and therefore are unable to provide effective care, 2) ED staff lacking the correct technical skills to accurately assess, and interact with, PWD in ED, and therefore are unable to provide effective care, or 3) ED staff do have appropriate understandings of priorities of care for PWD, and the correct skills and training to provide care accordingly, but are unable to do so due to external pressures or resource constraints. This research strongly suggests that the current experiences of care are the result of a combination of ineffective training- which leaves staff without core skills needs to provide effective care in ED- and systemic pressures and which create structural and procedural barriers which interfere with staffs ability to provide effective care.

This chapter will revisit the original three objectives of the research and address each in turn with reference to existing literature where available. Each of is associated with to a particular empirical phase(s) of the study, and or the literature review (See in brackets). The objectives were to;

1) Explore the current experience of accessing care in ED for PWD and their carers; specifically

a. Determine if there are certain features of the admission pathway or experience of care in ED that are considered problematic or especially positive *(Phase 1 survey)*

b. Identify what is important to PWD and carers when they access care in an ED (*Phase 1 survey and Phase 3 co-design)*

2) Explore the current experience of healthcare staff caring for people with dementia in emergency departments to gain understanding of;

a. The barriers to effective, safe care for people with dementia in the ED, and conversely, the facilitators of such care *(Phase 2 observation and interviews)*

3) Determine what structural and procedural changes would be required to enable provision of dementia friendly care in the emergency department in the NHS. *(Literature review, Phase 1 Survey, Phase 2 observation and interviews and Phase 3 Co-design)*

This chapter is divided into three sections reflecting the above. Following interpretation of the key findings, the potential limitations of the study will be discussed with specific reference to validity and reliability. The chapter concludes by presenting the key implications of this study for research, practice, and policy. As a pre-amble to this chapter, a summary of the various data collection points that have contributed data to this discussion is presented in Figure 30 on the following page.

Figure 30: Data collection points: Summary

Phase 1				Phase 2			Phase 3	
Literature Review	**Co-design of PWD/family survey using Expert panel**	**Testing and validation**	**Survey administration**	**Emerg. Dept. Document Review**	**Emerg. Dept. Observation**	**Emerg. Dept. Interviews**	**Co-design**	**Systematic Literature review**
Sept- 2015-March 2016 Narrative review of literature on dementia in acute care and older people in ED	April-June 2016 6 members of an expert panel participating in co-design informed by Delphi approach Bradford, UK	June-July 2016 Four 'think aloud' participants 10 test-re-rest participants Bradford, with participants recruited nationally	Sept 2016- May 2017 409 responses (403 included in analysis) Survey released nationally	May 2017 Documents from site 1 and 2 shared during preliminary meetings Hampshire, UK	August-September 2017 32 hours of non-participant observation- 16 at each site Hampshire, UK	August - November 2017 29 semi-structured qualitative interviews across sites Hampshire, UK	May –June 2018 Session 1: 6 participants, Bradford Session 2: 4 participants, Connecticut, USA	May-June 2018 38 Literature items on geriatric ED innovations from international sources

10.2 Current experience's of accessing care in ED

Two gaps in the literature were identified in the Background chapter. Firstly, there is limited empirical evidence about the experiences of PWD and their carers while they are in the ED. There is inadequate information about how these experiences differ or are similar to the experiences of older people without cognitive impairments. Secondly, there is a lack of understanding of what experiences or outcomes are equated with 'dementia friendly care' in the ED context. Consequently, there is a lack of understanding around the priorities and desired outcomes for ED care concerning PWD, and their carers. Due to this lack of information, it was necessary to design the survey using literature which either focused on the perspectives of PWD in alternative settings (i.e. hospital ward or community) or focused on the experiences and perspectives of older people without cognitive impairments. The survey, which constituted phase one of this research, offers evidence that addresses these gaps in part.

Firstly, it is clear that there is still considerable variability in the quality of dementia care in ED that is provided across England. Due to the geographical variety in sites, it was not possible to differentiate analysis by hospital or even by regional differences. However, based on the spread of respondents to the survey, it is still possible to conclude there is variability in the quality of dementia care. Notably, only 21 (6%) indicated they were very satisfied. (See figure 18, Pg. 113)

These findings parallel those of the 2006 report by the Royal College of Psychiatrists- which identified variability as a major concern, and highlighted improving the consistency of high quality dementia care as a priority for the NHS. Furthermore, 'Counting the Costs' (Alzheimer's Society, 2009), reiterated the need to improve acute care for patients with dementia. Additionally, increasing the provision of high quality dementia care in hospital was identified as a priority by the National Dementia Strategy (2009) and the Dementia Action Alliance 'Dementia Friendly Hospitals initiative' (2012).

The results of the survey here suggest that while improving dementia care has been repeatedly identified as a priority at the strategic and policy level, current approaches to improving dementia care appear not to be having the desired effect of ensuring a consistent and minimum, accepted standard of dementia friendly care across all English hospitals. Given that these strategic initiatives have not been effective in achieving the desired changes in practice, the investigation of potential barriers and facilitators to effective dementia care in this work, is well justified.

Secondly, statistical analysis of the survey data clarifies that the drivers of satisfaction for this patient/carer cohort are linked primarily to the patient's interpersonal experiences of care. These findings mirror the literature on older people's care in ED (Bridges et al., 2010; Grief, 2003; Nydén et al., 2003; Parke et al., 2011; Shankar, Bhatia, & Schuur, 2014) which indicate that satisfaction is principally related to interpersonal and interactional experiences of care. Furthermore Bridges et al (2010) and Nyden et al (2003) indicate that technical quality of care is often taken for granted by older patients and, as such, efforts to improve care should be weighted to give additional importance to interpersonal and interactional experiences.

In particular, the literature on older people's experiences of care stresses the importance of meeting higher level needs of identity, connection, and community through communication and shared decision-making. In this literature, communication was identified as an important moderating factor- where increasing quality and frequency of communication is associated with increased satisfaction regardless of other factors like length of stay or medical outcome of the visit (Bridges et al., 2010; Nydén et al., 2003; Shankar et al., 2014). The free text narratives provided by PWD and carers in the survey here support the conclusion that these higher level needs of connection, and maintenance of identity are equally important both to PWD and carers. The survey data also indicated that respondents felt frustration when their existing relationships and established caring roles are either devalued or unrecognized in the ED setting. Indeed shared decision making and perceived respect from

staff are also highlighted in the literature on older people's experiences as key determinants of satisfaction (Bridges et al., 2010; Nydén et al., 2003; Shankar et al., 2014).

The survey data also makes clear that condition specific knowledge is a unique driver of satisfaction for PWD and carers. Disease or condition specific knowledge is not identified as a core determinant of satisfaction for older people more generally, but an understanding of how dementia impacts behaviour and ability is clearly important for PWD and carers. Mindful of the strong carer representation within the sample, one potential explanation is the additional strain that carers report when the PWD exhibits distressed behaviours (Bridges et al., 2010; Whittamore et al., 2014). It is possible that an increased understanding of dementia is associated with more compassionate responses from staff, which in turn reduces carer strain and improves overall satisfaction.

In addition to exploring the determinants of satisfaction, this project investigated which elements of care have an association with a perceived dementia friendliness. The aim was to determine which elements are most associated with a perceived dementia friendliness to ensure quality improvement initiatives are appropriately focused. Similar to the results relating to satisfaction, these variables tend to focus on the interpersonal and interactional activities of care in the ED. In particular, communication and overall approach to care are highlighted as core features of dementia-friendly care. This is reflective of in the broader literature on satisfaction - both for older people in ED (Bridges et al., 2010; Nydén et al., 2003) and for PWD in acute care (Jurgens et al., 2012; Whittamore et al., 2014).

Equally interesting are the variables that showed limited correlation to perceived 'dementia friendly care'. In particular, the variable *"I was able to see signs directing me to facilities such as reception and toilets"* had a weak correlation (R_s 0.159), but the variable "*The physical space of the A&E or Minor Injuries Unit was safe and comfortable for someone with dementia*" had a significantly higher correlation (R_s 0.456). The importance of signage and way finding is often highlighted as an effective means of 'improving' the environment

and making it more dementia friendly (American College of Emergency Physicians, 2014; Dementia Action Alliance, 2012; Handley, et al Bunn, & Goodman, 2017; Parke & Friesen, 2015; Parke & Hunter, 2017). These results, however, suggest alternative adaptations may have more importance. For example, the provision of a quiet, (or quieter) space in both waiting and treatment areas has a stronger correlation with perceived dementia friendliness (R_s 0.412) and an increase in local noise is associated with increased anxiety or distress (R_s -0.280).

The movement of creating 'Dementia Friendly spaces' is gaining momentum with 133 acute trusts signing the dementia friendly hospitals charter (Dementia Action Alliance, 2018). Considering this momentum, it is essential to ensure the environmental changes that are being recommended and championed, are accurate reflections of the concerns of PWD and carers. Furthermore, the anticipated benefits must be tempered by a realistic appraisal of possible impact. Environmental design can contribute to improved quality of care, but only when the design features address major concerns- expressed by service users in the survey free text response- such as protecting privacy and dignity or preventing overstimulation. Cosmetic changes to the environment- such as paint or adding signage- are unlikely to have a significant impact on experience of care unless they are utilized in conjunction with a variety of cultural and procedural adaptations. The issue of environmental design is explored further in section 10.3.3 below.

The high number of statistically significant relationships between the items is unsurprising as the items were taken from literature on satisfaction for older people more generally. The hypothesis was that there was likely to be some relationship between the experiences of older people more generally and those of PWD, which appears to be confirmed by this study.

However, there were some unexpected findings in the survey. For example, no significant relationship was found between time of arrival at the ED and overall satisfaction or provision of dementia friendly care. Given feedback from staff- in literature and the advisory panel- who indicate they find it harder to

provide good care overnight, it might have been expected to find a relationship between time of arrival and overall satisfaction.

Given the important role carers play in acting as information stewards, and the proven safety implications of communication failures, (Sutcliffe et al., 2004), it is somewhat surprising that only 131 (33%) agreed or strongly agreed that the staff member who assessed them took time to ask about any recent changes in behaviour or memory. Furthermore, only 230 (58%) felt the patient was supported or encouraged to share information about relevant medical history. While this may be reflective of particularly effective information transfer between community and acute care- potentially removing the need for self reported history- it is more likely reflective of the demanding ED environment and the need for expediency. PWD frequently require an adapted environment and supportive approach to facilitate effective participation in care, and some suggest that ED staff do not understand, or cannot create, these conditions as they are balancing the needs of multiple patients with varying levels of acuity (Borbasi et al., 2006; McConnell et al., 2016; Moyle et al., 2011). Other literature reports that staff may resort to speaking solely to a carer or supporter if the PWD has difficulty communicating as it is perceived to be easier, faster, and more accurate (Bridges et al., 2010; May et al., 2001; Parke et al., 2013; Parke & Chappell, 2010). This approach can make the patient feel unvalued and increases the feelings of fear, worthlessness and loss of autonomy that some older patients report experiencing at the time of an admission (Bridges et al., 2010).

Another interesting facet of the data is the lack of statistically significant relationship between the age of the PWD and experience of care. Feedback from people with early onset dementia during co-design suggested that younger PWD may have poor experiences of care as they are perceived to need less assistance then older PWD who may be perceived as more frail or dependant. This relationship did not appear to be confirmed by the data. This is despite the considerable representation of people under 75 with dementia in this research. As noted in the findings, 22% of responses came from people under 75, which is

significantly higher than the overall proportion of PWD under 75 in the UK. A possible explanation for the large response rate from this particular group is the recruitment approach, which relied heavily on social media. However, it is important to be mindful of the overall number of people living with dementia who participated in this project; further research which utilises purposeful or stratified sampling would be required to accurately determine if people with younger onset dementia have different experiences.

10.2.1 What is important to PWD and carers when they access care in an ED?

The final phase of this project was the development of Dementia Friendly Emergency Departments Statements. This phase (3) aimed to highlight the elements of ED care that are most important to PWD and carers. For the full text of these statements see Appendix twenty-six.

When these co-designed ED statements are compared with the 'Dementia Friendly Hospitals Charter'- developed and launched by the Dementia Action Alliance in 2014-, there are a number of similarities. For example, the Dementia Friendly Charter includes the statements; if you are a person with dementia or their carer, you can expect to "*receive care from staff appropriately trained in Dementia Care*" and "*Staff [should] have a positive attitude towards you and your carer and [be] knowledgeable and skilled at meeting your needs*" (Dementia Action Alliance, 2012). The importance of training and attitude are equally highlighted in the Dementia Friendly ED statements here as core components of dementia friendly care.

Furthermore, the Dementia Friendly Hospitals Charter notes the important role of the carer- "*You, with the involvement of your carer, have choice and control in decisions affecting your care and support while you are in hospital and on discharge*"- which is also emphasized in the ED statements. The ED specific statements are more prescriptive in outlining the carer's rights and needs. It is possible this added focus on carers' rights and needs is reflective of the participation of multiple carers in the design process.

In the Dementia Friendly Hospitals Charter, the physical environment is touched upon- "*You are able to find your way around the hospital and the care environment supports your wellbeing and independence*"- and environment is also addressed in the ED statements. The ED statements however, make explicit reference to the importance of food, drinks, access to comforts, and provision of a quieter space. In contrast, the Hospitals Charter focuses on way finding, which was demonstrated here to have limited association with dementia friendly care in the ED setting. This might be explained by the extended periods these patients spend on wards. Whereas patients and carers may accept the need to ask for assistance in way finding in an environment they consider transient- like ED; longer term care environments having different design requirements.

The ED statements make explicit reference to dignity, compassion, and respect as the first principles of dementia friendly ED care. These words do not appear in the Dementia Friendly Hospitals Charter- though reference is made to a positive attitude towards dementia. On the Dementia Action Alliance (DAA) webpage, which discusses creation of the Dementia Friendly Hospitals Charter, it states development was facilitated by the DAA in consultation with clinicians and policy makers. No explicit reference is made to substantive engagement or involvement of PWD and carers during the design processes. The explicit reference to dignity, compassion and respect are therefore an important difference in these documents, which could be explained by the participation of PWD and carers in the design process of the ED statements.

10.2.2 Key Messages Phase One

In summary the findings reported here support the view that there is considerable congruency between ED care elements that drive satisfaction for older people generally and for PWD and their carers. Both groups place high value on the interpersonal interactions and experiences of care. Therefore, interventions that focus on improving interpersonal or interactional elements of care in ED are likely to have a positive impact on PWD and older patients more

generally. However, there is a key difference between PWD and other older people. PWD and carers place a premium on condition specific knowledge and a related ability to adapt care to ensure it is appropriate for the PWD. Therefore, quality improvement efforts should emphasize education- in particular translating awareness into adapted practice. For an ED to be dementia friendly it must combine positive interpersonal interactions- that are beneficial for all older people- with disease specific knowledge and approaches to care that are sensitive to the needs and experiences of PWD.

10.3 Barriers and facilitators of effective care- as identified by ED staff

Phase two identified several barrier and facilitators of effective, safe care for PWD in ED. The key barriers reported by staff included;

1) Lack of effective communication- both between provider to provider (systems) and patient to provider (interpersonal).
2) Increased demand for emergency care which has outpaced investment,
3) Training which is misaligned to the skills staff need to effectively interact with PWD, and
4) Organisational cultures that do not support or facilitate person centered care, or cultures that accept normalisation of deviance (Vaughn & Samudra, 1996).

In contrast, the facilitators of good care included:

1) Easy access to personal and medical information- either via effective information transfer systems or interpersonal interactions.
2) A physical environment which enables the provision of person centred and dignified care,
3) Sufficient numbers of well trained staff
4) Access to specialist staff for support where needed and appropriate.

5) An organisational culture which values person centred approaches to care and facilitates the provision of 'time and space' to provide holistic care.

These barriers and facilitators have been split into four sections: communication, environment, staffing and training, and organisational culture. As this research aimed to find positive deviants, the main focus of these sections is on the facilitators of good care.

The sections on communication, environment, and staffing and training present previously identified barriers in a table, and the focus of the discussion is solely focused on facilitation. The section on organisational culture takes a comparative approach- reviewing aspects of the culture from both sites to provide commentary on the potentially generalizable impacts of organisational culture in ED on the provision of effective dementia care.

10.3.1 Communication.

Effective transfer of information- either via official information sharing agreements, patient self reports or family involvement - has been identified here as a key facilitator to the provision of effective, safe dementia care in ED. However, incompatibility in information technology systems and the limitations of patient ability to share accurate medical and social history due to cognitive impairment can be major barriers to effective communication. Major barriers identified by staff- and their relevance to broader literature are presented below.

Figure 31: Communication Barriers

Phase Two finding	**Literature**
Inability to access community records negatively affects ability to provide good care	• Improving IT is forefront in priorities of the NHS in part due to recognition that IT failings contribute to sub-optimal care (Hancock, 2018). • Decentralization and attempts to implement IT reform on smaller scales "*inevitably leads to sub-optimal usage and communication barriers due to fragmentation of the infrastructure*" (Avison & Young, 2007, pg70).

Poor communication impacts continuity and quality of care.	• Provider to provider continuity of care is recognized as valuable for improving the care of many patients, especially those with chronic illness, disability or functional limitation (Anderson & Knickman, 2001) • Transitions are points of risk for patients with complex, chronic care needs, and health systems "often fail to ensure *that the essential elements of the patient's care plan that were developed in one setting are communicated to the next team of clinicians*"(Coleman, 2003, Pg 549).
Inability to communicate/ lack of information, can increase risk for PWD in ED	• Increased risk of inaccurate diagnosis (Australian and New Zealand Society for Geriatric Medicine, 2015; Hwang & Morrison, 2016; McClelland & Sorrell, 2015; Melady & Perry, 2018; Perry et al., 2018) • Communication challenges impact the safety of the PWD in ED if impairment in expressive communication leads to difficulty gathering information on current condition or an inability to express unmet psychosocial needs (Andrews & Christie, 2009; Parke et al., 2013; Tsilimingras et al., 2003). • A quarter of inpatient admissions from ED occur in the last 10 minutes of the four-hour period, suggesting admission is sometimes seen as the only option to avoid a 4 hour penalty breach (Munir, 2008; National Audit Office, 2018)
If the patient cannot communicate independently, alternatives to patient-to-provider information transfer are required and desired.	• 85% of polled public expressed a desire for any healthcare professional to have access to GP records (EMIS Health, 2014). • 58% of polled public are not aware that ED staff cannot access their electronic health records held by GP's(EMIS Health, 2014). • 61% express concern that failure to share information may have a negative impact on their health due to treatment delays or medical errors (EMIS Health, 2014). • Greenhalgh et al (2008) suggests patients are comfortable with information being shared between health professionals, but many are unaware of 'opt in' schemes which enable this (Greenhalgh et al., 2008).

Facilitators

Staff require accurate and contemporary medical and social history to provide effective care. To acquire this information, staff utilize a variety of strategies including; provider to provider data sharing agreements, contacting colleagues in the community, or relying on the patient or family to share information.

Official provider-to-provider data sharing agreements were most successful in facilitating effective, timely information transfer. At Site Two the frailty team are employed by the community health trust, and therefore have access to all patient data in primary care – including GP notes. The ED doctors have also been given honorary contracts with the community provider so they are able access notes the some primary healthcare record. These honorary contracts allow rapid, uncomplicated access to a breadth of information. In contrast, at Site One, there is no provider-to-provider data sharing agreement, so staff instead call individual GP surgeries to request access to community notes. This system can be helpful, but is also time and labour intensive, and only available during regular working hours. Both approaches facilitate access to information; however, the provider-to-provider approach clearly streamlines the process.

Recent research suggests that 85% of patients support all healthcare professionals having access to GP records, and 58% are not aware that ED staff cannot access their electronic health records (EMIS Health, 2014). Greenhalgh et al (2008) suggests that many patients are unaware of 'opt in' schemes which enable acute care staff to access their medical records, despite being comfortable with their information being shared between health professionals (Greenhalgh et al., 2008). This suggests there is considerable patient support for broader integration of electronic health records to facilitate more effective access to pertinent patient records.

Despite the broad public support and persistent calls for better electronic record integration, progress has been slow (Clarke et al., 2017). The national programme for IT (2002) aimed to create a single electronic health record that could be accessed using a national infrastructure by 2010- however, this failed

to be implemented. In 2014, the Carter Report recommended it would be wise to invest in an interoperable IT systems NHS to enable information sharing across the NHS (Coles, 2016) but minimal progress has been made to date on transferring that idea to practice (Clarke et al., 2017). Avison and Young (2007) and Clarke et al (2017) suggest piecemeal adoption of IT innovations and decentralization of the NHS has led to smaller health economies making significant investment in their own IT system, and thus are unwilling to invest in further changes. EMIS Health (2014) and Greenhalgh et al (2008) also cite privacy concerns as a barrier to implementation. However, despite these challenges, better information sharing between primary, community, and acute care appears to be a means of improving quality and safety of care for PWD in ED. Improved information transfer at points of transition is particularly pertinent for PWD, as the cognitive impairment associated with many forms of dementia may impair ability to communicate or self advocate. Traditionally, self advocacy or patient reported data is treated as a 'layer of defense' (Reason, 1990) in ED care, acting as an additional layer of protection for the patient. Given that this patient group may not be able to perform that function, there is increased imperative to ensure the broader 'system' compensates for this absence.

When official information sharing channels are not available, or there is a delayed access, the patient's family can act as a 'layer of defence' by facilitating information transfer. Families are able to provide medical history and can interpret behaviors, which enables staff to provide informed care. A similar finding was reported by Kelley (2017) who concluded that families play a crucial role in facilitating good care for relatives with dementia after an ethnographic exploration of families' knowledge and expertise in delivering care. Substantive involvement - both shared decision making and involvement in direct care- was reported as desirable by many carers in this project. This is again reflective of Kelley's (2017) findings, which suggest carer involvement in decision making is essential to satisfaction and good outcomes. Kelley concludes that unfortunately neither occurs consistently in the NHS.

These findings are also reflected in broader literature on improving dementia care, where the importance of treating the patient and carer as a dyad is clearly indicated in both policy and research (Bridges et al., 2010; Coleman et al, 2003; Chalmers, & Rosenbek, 2011; Department of Health, 2009, 2015; Kelley et al,, 2010; Parke et al., 2013). When reporting on the development of a 'ready for hospital' admission toolkit Hunter, Parke, and Shultz (2016) found that family carers reported strong desires to participate in the care of their relative, and felt information transfer was a core component of their function as 'carer'. Others, such as Bridges (2010) and Jurgens et al (2012), also highlight the benefits to satisfaction and patient safety which can occur when the carer feels listened to and involved.

Therefore, encouraging and facilitating active involvement of carers in ED is likely to improve quality and safety of care by enabling family to act as an additional layer of defense. Therefore it is essential to ensure the physical environment and culture of care actively support and encourage carers to stay and remain involved- this is explored further in sections 10.3.3 and 10.3.7.

10.3.2 Key messages

The finding that ineffective communication is a barrier to good care is unsurprising given the breadth of evidence that effective and accurate communication is essential to ensuring good outcomes and preventing error (Carayon et al., 2014; Carayon & Wood, 2010; Gawande, 2011; Parry, 2011; Sutcliffe et al., 2004; Woodhall et al., 2008). In particular, Sutcliffe, Lewton and Rosenthal (2004) found that communication errors are one of the most commonly cited contributory factors to error in medical care. This was attributed to the important role communication plays in navigation of complex networks of care and working in large, often multidisciplinary teams. Therefore information barriers, or miscommunications are major risks to patient safety. This risk is particularly pertinent for PWD as the 'safety net' of (patient) self-advocacy or a patient reported history may be undermined by cognitive impairment (Coleman, 2003; Parke et al., 2013). Ensuring effective flow of information from the

community into acute care is vital to improving the quality and safety of dementia care in ED.

Careful consideration of how to optimize IT integration to enable easy access to community care records will support ED staff by facilitating transfer of important medical history. Similarly, it is essential to recognize the role of family or other informal carers in providing information. Due consideration must be given to the physical, social and psychological needs of carers in ED in order to facilitate their effective involvement and maximize their ability to provide positive contributions.

10.3.3 Environment

The physical environment plays an important role in influencing experience and outcome of care. The impact of crowding and lack of space, as well as lighting, acoustics and layout emerge as key findings. The environment is largely considered a barrier to effective dementia care- although with certain adaptations and in certain situations it can facilitate good care.

Figure 32: Environmental Barriers

Phase two finding	Literature
Consistent and increasing demand for emergency care which is causing strains on the physical and social infrastructure of ED- i.e. practicing hallway medicine	• Emergency admissions increased by 24% between 2007/8 and 2016/17 (National Audit Office, 2018) • Bed pressures caused by poor patient flow– especially in the winter- are leading to extended wait times and crowding in ED (Appleby, 2016; Evans, 2017; Fisher & Dorning, 2016). • In addition to overall increases in ED attendances, there have been significant increases in the number of people over 65 attending the ED= 53% of growth in emergency admissions is attributable to people over 65 (National Audit Office, 2018) • For PWD experience of care is strongly influenced by excessive noise and overstimulation (Andrews & Christie, 2009).
Caring for patients outside of traditional	• Hallway medicine, or 'boarding', can have profoundly negative impacts on patient safety, having effects on both morbidity and mortality

'clinical spaces' such as bays or rooms in ED has negative impacts on patient safety	(Carter, Pouch, & Larson, 2013)
	• In particular, crowding in the ED has been linked to;
	  ○ Increased risk of medication delays and adverse events relating to medication administration (Sri-On et al., 2014)
	  ○ Poor pain control in patients with hip fracture (Hwang et al., 2006), and
	  ○ Increased length of stay, which in turn is associated with increased risk of delirium (Ackroyd-Stolarz et al., 2011; Émond et al., 2017).

Working in overcrowded departments has a negative impact on staff morale	• Crowding has negative impacts on workplace satisfaction for both physicians (Rondeau & Francescutti, 2005) and nursing staff (Elmqvist et al., 2012; McConnell et al., 2016).
Excess noise and lack of diurnal lighting can cause distress to patients and make it challenging for staff to provide good care.	• Excess noise and overstimulation is associated with increased anxiety- survey finding • Diurnal lighting is recommended, but rarely used in ED setting (Parke & Friesen, 2015) • The environment should support and promote independence, while also enabling staff to do their job effectively (American College of Emergency Physicians et al., 2013)

In this context of increasing demand and lack of investment, the physical environment negatively impacts the ability of staff to provide effective care for PWD. Facilitating good care therefore requires adaptations or adjustments that remove these environmental barriers. Good care is facilitated by ensuring potentially high risk patients- such as PWD- are in appropriate, clinical spaces, within an environment that minimizes environmental stimulus which can cause distress or increase risk of harm.

Good patient flow through the department is reported as a major facilitator of good care. When demand for services is equivalent to resources available- both physical and human- the staff are able to facilitate quicker transitions. This in turn reduces the amount of time spent in an over stimulating

environment and reduces the probability of the patient experiencing distress. Additionally, when the flow is good, a PWD is typically cared for within regular clinical spaces- i.e. individual bays or rooms- rather than hallways or shared bays. In these designated clinical spaces it is easier to control the patient's immediate environment and- in some cases- reduce environmental stimulus that can cause distress. Furthermore, these designated clinical spaces are more easily adapted to support the PWD with provision of seating or a foldaway bed to support a carer staying comfortably.

However, challenges with flow and access are complex, multisystem, and multi-transitional. They persist despite numerous potential solutions being proposed to address crowding in ED and beyond (McHugh & Dyke, 2011; NHS England, 2015; Royal College of Emergency Medicine, 2015). To date limited progress has been made in addressing crowding at the national or regional level. Therefore, a locally derived alternative to reduce the negative impacts of extended periods in ED is a potential solution.

One such solution would be the creation of a seperate geriatric or older persons ED. The creation of a separate, purpose built, space for older patients and those with dementia could counteract the challenges posed by crowding and the unsuitable enviroment by removing the 'at risk' patient from the enviroment. A separate unit or separate area within the ED specifically for older people is already regognised as 'gold standard' ED care for older people (American College of Emergency Physicians et al., 2013; Banerjee et al., 2012; Carpenter et al., 2014; Hogan et al., 2014; Hwang et al., 2013). The literature suggests that a separate enviroment could better address the needs of older people (or PWD) through reduction of stimulus and preservation of a calm, healing enviroment. This enviroment is believed to assist in achieving desireable health and social outcomes by 1) reducing risk to patients by removing risks such as excess medical equipment that causes tripping, reducing stimulus to decrease risk of iatrogenic delirium, and reducing unneccesary medical procedures (Hwang and Morrison, 2016), and 2) ensuring early, comprehensive review by clinicians with specific geriatric training which

facilitates rapid diagnosis and discharge back to the community, thus preventing hospital aquired deterioration (Melady and Perry,2018).

While there is currently a lack of empirical evidence to demonstrate comprehensive benefits of geriatric ED's, evidence from alternative settings- such as wards and long term care- supports the conclusion that adapting the enviroment could improve patient outcomes(Day, Carreon, & Stump, 2000; Fleming & Purandare, 2010). Additionally, this separate unit could facilitate early review by specialist clinical staff, which in turn enables more comprehensive and holisitic care from the start of treatment (Aldeen et al., 2014; American College of Emergency Physicians et al, 2013;. Banerjee, Conroy, & O'Leary, 2012; Melady & Perry, 2018; Rawson et al., 2017).

A parallel can be drawn here between the movement towards geriatric ED's and the emergence of paediatric ED's in the last three decades. A growing recognition that children have unique social and medical needs lead to the development of early paediatric ED's which were staffed by paediatricians and focused entirely on meeting the distinct needs of child patients. From these early paediatric ED's, emerged emperical evidence that children treated in specialist units had a range of positve outcomes including improved survival and better experiences of care (Durch & Lohr, 1993). From this initially limited body of knowledge, early adopters and pilot studies eventually demonstated the unquestionable benefits of distinct paediatric units, leading to additional research, training opportunities, and eventually widespread adoption of the separate care model (Committee on the Future of Emergency Care in the United States Health System, 2007).

Similar to children, PWD have a unique set of care needs which typically cannot be met within the general ED. This patient group would benefit from treatment by specially trained staff who could provide holistic and informed assessments based on geriatric care principles (Melady & Perry, 2018). Changing the physical enviroment to facilitate improved care is a widely reported adaptation by geriatric ED's (Hogan et al., 2014; Ryan et al., 2017). Treating older patients and PWD in a purpose built enviroment could remove some of the

enviromental features which cause distress, as the design and layout could be designed specifically to meet the needs of this particular patient group.

In addtion to anticipated patient benefits, changing the enviroment also could have staff benefits For example, both staff and carers report being frustrated with excessive noise waking the PWD while they were sleeping in the ED. This caused frustration, particularly if it had taken considered investment of 1-1 staff time to facilitate this initial restful state. Therefore, changing the environment to reduce stimulation could make it easier for staff to care for patients if they are not repeatedly called to settle a distressed patient with dementia who has woken in an unfamiliar environment.

One potential explanation for this widespread adoption of environmental adaptation is the appeal of pre-defined, self limiting, auditable change. The presence of existing guidelines on best practice in adapting the ED environment (American College of Emergency Physicians et al., 2013; Banerjee et al., 2012; Kelley et al., 2010; Parke & Friesen, 2015) mean the proposed changes have precedent and clear guidance making it an appealing project for budget holders. However, some caution must be exercised. While altering the environment to reduce stimulus, or providing a separate space entirely to remove the PWD from the overcrowded ED may offer some benefit, adapting the physical environment alone will not improve care. Changes to the environment can remove some staff-identified barriers to provision of person-centered care -but environmental design must complement, not supplant broader reforms to make the ED dementia friendly. It is important to be mindful of the findings from Phase One of this research, which demonstrated a limited correlation between satisfaction and dementia friendliness, and items relating to the physical environment. Nevertheless, there are opportunities to incorporate age friendly elements if ED's are intending to undertake renovations or redesign.

10.3.4 Key messages

Both the observation and interview data strongly suggest that the physical environment of ED is currently a barrier to provision of effective care. The

physical environment not only fails to provide layer of defense for PWD who experience high risk of avoidable harm, but it in fact increases the risks they are exposed to. Failure to implement age friendly design principles leaves staff or family supervision as the only defense mechanism to mediate the interaction between the patient and this unsuitable environment. These challenges are compounded by crowding and increasing demand for emergency and inpatient care- issues with wide ranging consequences across health and social care systems. Locally owned and implemented solutions- such as creation of separate care spaces for PWD and older people- can offer a solution to minimize or moderate the effects of crowding. However, as the population ages and demand for inpatient care grows, it is imperative that a 'full systems approach' to addressing crowding and increased demand is utilized. Adapting the physical environment of ED's may have some positive benefits in facilitating better care for PWD, but unless the broader issues of access, flow, and access to social care in the community to facilitate expedient discharge are implemented, it will be difficult to ensure a substantial, sustained impact on care. Addressing crowding and access challenges will require financial and political commitment across multiple systems including acute, primary and, social care.

10.3.5 Staffing, Training and Education.

The number and skills of staff in ED plays a vital role in determining experience of care for patients. For clarity, safe staffing is defined here as "*sufficient nurses with the required skills to meet patient needs, and that they are organised and managed in a way that enables them to deliver the highest quality of care possible"* (Recio-Saucedo et al., 2015, pg 888). The major facilitator of effective care for PWD in ED is sufficient numbers of staff to provide safe staffing, with an appropriate skills mix, and the correct training.

Staffing, training and education are relevant across both nursing and medical care staff. However, the small number of physicians who participated in this research makes it challenging to draw any firm conclusions about medical staffing, and as such this section focuses on nursing. To briefly reference the

literature on physician education the National Audit on Dementia Care (2009), Dewing and Dijk (2016), and Gladman et al (2012) all report that physicians feel more adequately trained, and confident in approaches to dementia care when compared to nurses and healthcare assistants despite the later having more regular interaction with PWD once they are in care.

Figure 33 Staffing and training Barriers

Phase two findings	Literature
Insufficient numbers of staff is a significant barrier to provision of effective dementia care in the ED.	• Royal College of Nurses found that 58% of nursing staff at NHS sites reported their previous shift had a shortfall of one of more registered nurses (Borneo, Helm, & Russell, 2017).
When shift are run with a full rota but insufficient adaptation to account for surges in demand, the staff ability to provide safe and person centered care is extremely limited	• 53% felt the care of their patients was compromised by staff shortages(Borneo et al., 2017) • 36% felt the pressures on staffing meant they had to leave necessary patient care undone (Borneo et al., 2017) • Finding an optimal staffing model for the ED is challenging is the inability to predict or control patient volume and acuity (Wolf et al., 2017).
Safe staffing in ED is intimately linked with patient safety and experience of care- especially for PWD	• Inadequate staffing is linked with increased patient morbidity and mortality (Aiken, Sloane, Bruyneel, & Heede, 2015; Berwick, 2013; Francis, 2013; Griffiths et al., 2014; Kane, Shamliyan, Mueller, Duval, & Wilt, 2007; Robinson, Jagim, & Ray, 2005) • Persistent mismatch between the demands of patient care and available staffing resource is leading to burnout, disengagement and high rates of staff turnover (Borneo et al., 2017; Wolf, Perhats, Delao, Clark, & Moon, 2017).
The frequent mismatch between medical acuity and requirements of care for PWD in ED poses a challenge as the patients actual often exceed what would normally be expected for a patient with the same presenting	• Hayes and Ball (2012) found that traditional workforce planning approaches are insufficient when there is large number of older patients as their needs can vary widely based on frailty, cognition, and involvement of family among other things.

complaint who did not have Dementia	
Overreliance on of specialists can be barrier if it leads to delays in patient care or abdication of responsibility.	• Jack, Oldham, & Williams (2002) found that senior stakeholders feel that the clinical nurse specialists may be de-skilling the general nursing and medical staff • Many senior managers worried the presence of specialists might tempt general staff to abdicating their responsibility (McGee, Castledine, & Brown, 1996)
Nurses report that the training they received was excessively focused on the biomedical process of aging and failed to provide effective guidance on best practices for interacting with people with cognitive impairments or managing behavioural and psychological symptoms of dementia.	• Lack of effective education and training in dementia care has been recognised as a major contributory factor to poor quality of care in hospitals (Department of Health, 2009; Dewing & Dijk, 2014; Gladman et al., 2012) • Gladman et al (2012) suggest there is a fundamental misalignment of nursing training with the needs of PWD. • The current training model places an emphasis on 'activities' of medical care, and fails to "*focus explicitly on relationships understanding behaviour from the patient's perspective or recognizing the impact of their cognitive deficits*" (Gladman et al., 2012, Pg 16). • Dewing and Dijk (2016) also indicate that education which focuses predominantly on medical needs in acute care leads to nurses focusing primarily on the medical care of PWD, which- when combined with poor understanding of dementia - can lead to poor experiences of care. • This tendency to focus on the medical task- at the expense of taking advantage of an opportunity for person centered care or relationship building- was also noted by Clissett, Porock, Harwood, & Gladman, (2013).
Formal education failed to give nurses the skills they needed to confidently interact with, and care of, PWD.	• Dewing and Dijk (2016) reported several studies share a common finding of nurses feeling they do not have sufficient skills or education to care for people with dementia. • Borbasi et al (2006) found that nurses report managing behavioral and psychological symptoms as one of the most challenging aspects of nursing patients with dementia.

Deficiencies in training lead to suboptimal care practices as 'workarounds'	• The lack of skills and confidence to address behaviors that challenge has led to nurses requesting that physicians prescribe sedatives or antipsychotics to PWD to control these behaviors. (S. Banerjee, 2009; Borbasi et al., 2006; Gladman et al., 2012; Wendy Moyle et al., 2011) • Anti-psychotics and sedatives have been linked to a range of safety risks, such as falls and delirium, and poor outcomes such as extended stay and advanced trajectory of cognitive decline for PWD (Banerjee, 2009)

The major facilitator of effective care for PWD in ED is sufficient numbers of staff, with an appropriate skills mix, and the correct training. As noted above in the barriers section, there are major challenges with ensuring shifts have sufficient staffing- especially nursing staff. Even when rotas are fully staffed, the staff numbers are sometimes insufficient to ensure effective care. Some stakeholders feel a minimum safe staffing ratio would be an appropriate first step in addressing the challenges of staffing, but NHS Improvement (NHSI) claim a safe staffing ratio would be overly prescriptive and unable to appropriately address the complexity of resource requirement planning in ED. In lieu of a minimum ratio, NHSI guidelines state that all organisations should have appropriate escalation processes if staffing is inadequate for the number or acuity of the patients. Furthermore, they propose recommendations for the development of models of care, planning, and monitoring tools. Critics- such as the Royal College of Nurses- claim that these non-binding recommendations are insufficient and will not lead to meaningful changes in work force planning or better working conditions for staff (Borneo et al., 2017). Additionally, evidence from this research and others (Haynes and Ball, 2012; Parke et al, 2013) suggests that escalation models which rely solely on medical acuity or overall numbers of patients may fail to account for the additional needs of PWD and the demands on nursing time (Hayes & Ball, 2012).

Therefore, in order to ensure safe and appropriate staffing each unit should have a comprehensive escalation policy which makes explicit reference

to the possibility of patients (such as PWD) having care needs which exceed what may be expected given medical acuity or presenting complaint. Finding an appropriately sensitive workforce and escalation model for ED is a recognised challenge as hospitals are unable to predict acuity or control patient volume in ED (Wolf et al., 2017). The ED appears to be needs-driven and reactive, making it difficult to anticipate exactly what resources will be needed for a given shift. One possible option is to expand the use of 'bank staff' to respond to surges in demand. However, the NHS workforce planning review (Rachael et al, 2015) suggest that the use of temporary staff to fill rotas had cost approximately £980 million in the NHS in England in 2014/15. Rachael et al (2015) further note that increased use of temporary or bank staff results in deteriorating financial stability of acute trusts, higher wage bills, poor continuity of care and low staff morale (Pg.19).

While this option would ensure the additional resources are only called in when required, there are a number of issues with increased use of temporary staff. For example, working in an unfamiliar team is a known contributory factor to medical error (Lawton et al., 2012) and use of temporary staff in ED has been linked to increased 'severe harm' medication errors (Pham et al., 2011). As an alternative, a flexible working policy, which offers additional hours to existing ED staff during times of high pressure, could be implemented. However, evidence gathered during observations here suggests that additional shifts are frequently offered to ED staff, and managers still struggle to fill rotas.

The challenges of unfilled rota's can be linked to the wider national challenge within nursing shortages due to reduced numbers of students entering training, poor retention of staff, and challenges with recruitment from alternative sources such as other countries (Royal College of Nursing, 2018a, 2018b). The current political and social climate in the UK is likely to exacerbate these challenges in the coming years (Royal College of Nursing, 2018a) as immigration of health care professionals from Europe slows.

Given these challenges with staff recruitment and retention, an alternative, or additional option, is critical appraisal of what skills are required to

address the unmet needs in the department. These findings, and feedback from the Royal College of Nursing, suggests that the missing elements of care for PWD, and care elements most likely to get missed or forgotten at times of pressure, are the "non-medical", holistic care (Borneo et al., 2017; Royal College of Nursing, 2018b). Relationship centered care, communication, and the feeling of being 'cared for' are all intimately linked with perceived quality of care and satisfaction for older people and PWD (Bridges et al., 2010; Nydén et al., 2003). Therefore, there may be opportunities to improve care of this patient sub-population without requiring additional registered nurses or physicians.

Several staff raised the potential of improving quality though increasing numbers of staff focused specifically on 'holistic care' in the ED. Many registered nurses indicated they felt their clinical duties interfered with their ability to provide 'care' in the ED. Some complained this medical/ technical focus in ED has diluted their core 'nursing function'. Others feel their function in ED necessitates a focus on ensuring survival of the most acutely ill patients- even if this comes at the expense of providing a holistic approach to care. Overall, the consensus from ED nurses is that there is value in ensuring certain ED roles that are focused explicitly on 'caring' functions. Several staff suggested increasing the number of health care assistants in the department could fulfill this purpose. This diverges slightly from the broader literature on safe staffing, which typically reports negative patient impacts as a result of increasing numbers of healthcare assistants (Aiken et al., 2015; Borneo et al., 2017; Hayes & Ball, 2012; Kane et al., 2007; Wolf et al., 2017). However, respondent felt strongly that having staff entirely devoted to care and comfort of PWD would improve experience of care. Additionally, they felt it might improve safety as the extra staff could facilitate opportunities for supported mobilization, provide additional supervision, and offer companionship to patients who are disoriented or distressed. It is important to note here that the desire expressed by staff is for additional resources focused on caring, not a direct decrease in registered nursing staff with a compensatory increase in health care assistants.

Furthermore, given the stated need for additional resources devoted to

care and companionship rather than additional skilled nursing resource, another option is the use of volunteer based models to supplement paid workforce. Several examples of volunteer based models exist including the Care and Respect for Elders (CARE) at Mt Sinai Hospital New York and the Maximizing Aging Using Volunteer Engagement (MAUVE) program at Mt. Sinai Hospital in Toronto. These models aim to provide companionship, care, and comfort to older people in ED, alongside one to one support for patients, which nursing staff are frequently unable to provide given the demands of managing multiple patients. Evaluation of the CARE program found that over 90% of the 'intervention' provided by CARE volunteers is individual attention- mostly talking and re-assurance, which improves care of the older patient by meeting the needs for connection, communication and caring (Sanon et al., 2014). No clinical outcome data was measured to assess the impact of the program, but a qualitative evaluation revealed positive reactions from patients and acceptability by ED staff (Sanon et al., 2014). The MAUVE program in Toronto uses a similar 'care and companionship' model, and is scheduled for impact and efficacy assessment in 2018/19 (Sinai Health System, 2018). Interestingly, the use of volunteers to meet the 'care and companionship' needs of PWD was raised as a possible means of improving quality and safety by ED staff (see appendix twenty five). As with any volunteer model- the success of the program would depend on providing effective training, clear responsibilities and roles, and good management of the volunteer workforce (Grossman & Furano, 1999).

Another key element of safe staffing in the ED for PWD is the involvement of specialist staff. Specialists- such as frailty teams or dementia support workers- have essential (geriatric) core competencies and support the effective functioning of the ED. It is important to explicitly define the core functions of the specialist staff, as problems arise when specialists are over-relied upon or used inappropriately. The primary purpose of frailty teams is to provide highly skilled assessment of geriatric patients with complex care needs. Their training means they are confident interacting with PWD and they feel uniquely able to provide holistic care and comprehensive assessment. In

contrast, the primary role of dementia support workers in the ED is to provide companionship, orientation, and comfort, which in turn enables the registered nurses to focus on completing routine diagnostic assessment and delivering interventions. Their training and skills focus on the development of relationship building in a one to one setting. While senior dementia support workers may be registered nurses, the majority are health care assistants.

The involvement of specialist staff is a facilitator to good care when they are used appropriately, and with due consideration of their intended purpose. There are widely recognised benefits of early, comprehensive review by specialists who have specialised training in geriatrics- in particular enabling the effective review of complex care needs, (Aldeen et al., 2014; American College of Emergency Physicians et al., 2013; Banerjee et al., 2012; Melady & Perry, 2018; Rawson et al., 2017). Additionally, the importance of relationship focused care and companionship is recognised as essential for improving experience- and would very probably improve safety, both for older people, and PWD (Bridges et al., 2010; Nydén et al., 2003; Parke et al., 2011; Sanon et al., 2014). When the specialists are used accordingly, it assists ED staff by offering expert assistance and providing focused support for the PWD that would otherwise be impossible given the demands of ED.

Nevertheless, the involvement of specialist staff can become a barrier if ED staff becomes overly reliant upon them, potentially leading to delays in patient care. This was particularly notable with regards to patients being held overnight to be assessed by frailty teams. While this may have been appropriate if the patient has particularly complex needs, the frailty nurses believe many ED staff refer patients to frailty due to a lack of confidence. This concern about specialists resulting in general staff 'abdicating their responsibilities' or becoming deskilled was previously noted by McGee et al. (1996) and Jack et al. (2002). The respondents reported concern that over-reliance on the frailty teams masks a need for more, and better quality, training in geriatric conditions and effective communication skills to support best practice in the care of PWD.

This feedback from specialists is unsurprising given that ED staff identified misaligned training as a key barrier to their ability to provide good care for PWD in ED. To briefly re-iterate, the major challenges with staff training are

1) An excessive focus on the biomedical process of aging,
2) Failure to provide effective guidance on best practices for older patients with complex needs
3) Task focused nursing, and
4) Failure to ensure nurses have the skills they needed to confidently interact with, and care for, PWD.

These deficiencies lead to staff relying on 'workarounds' or providing sub-optimal care.

Addressing these misalignments in training can be approached from national/regional and/or local levels. At the national level altering medical and nursing curriculums to include more dementia focused training and is a potential avenue to address the currently identified deficiency. This recommendation is consistent with conclusions from the National Dementia Strategy (2009) and the (British) Prime Ministers Challenge on Dementia (2015) that state dementia education requires improvement. The 2013 mandate from the Department of Health to Health Education England clearly indicated that by 2015, Dementia training should be part of undergraduate nursing curriculums nationally (Department of Health, 2013). However, there is a growing understanding that formal, knowledge based education may not translate effectively into improvements in practice (Cowdell, 2010; Surr et al., 2017) and there is a persistent risk that training could become an administrative 'tick box' and fail to result in widespread changes to practice (Collier, Knifton, & Surr, 2015).

Another possible change that could be enacted at the national level is a shift in the focus of nursing education. Gladman et al (2012) suggests the current training model emphasises 'activities' of medical care, and fails to "*focus explicitly on relationships, understanding behaviour from the patient's perspective, or recognizing the impact of their cognitive deficits*" (Pg. 16). This model, they claim, is designed to focus attention on physical matters and away

from concerns relating to mental matters. The same finding is restated by Dewing and Dijk (2016) who indicate that education which focuses predominantly on medical concerns leads to nurses focusing primarily on tasks of care. This in turn leads to poor experiences of care for PWD who require more person centered or holistic approaches. This tendency to focus on the medical task- at the expense of taking advantage of an opportunity for engaging in person centered care - was also noted by Clissett, Porock, Harwood, & Gladman (2013). The result of this 'task based' training is nurses who lack the confidence to engage with PWD in clinical settings. Therefore, integrating more opportunities for training which focuses on relationship building approaches (such as communication training) is likely to improve confidence of staff, and subsequently improve care. This recommendation again reflects the literature, as Eggenberger, Heimerl, and Bennett (2012) found that providing communication skills training to staff in can significantly improve quality of life, aid wellbeing, and increase the quality of positive interactions for PWD in a number of care settings.

Many staff reported the most valuable training they received was in the workplace, as workplace training translated more effectively in adapted practice. This was felt to be particularly relevant for ED staff, as the ED is a unique and fast paced environment. ED staff felt approaches that are developed for a ward or community care setting may not translate well to the ED context, and therefore context-sensitive training is required. Furthermore, staff reported a clear desire for dementia training that is skills based and hands on. The 'hands on, skills based' approach was also recommended as a preferred training approach by the 'What Works in Dementia Training?' study (Surr et al., 2017) and is further supported by a report by the Commission on Dignity in Care for Older People (2012) which recommended more extensive use of active learning strategies and practice-based development programmes in the workplace. The clear preference for skills based training indicates that awareness focused (Tier One) dementia training- as defined by Health Education England- is wholly insufficient for clinical staff who require, and desire, training which develops

relevant clinical competencies. This conclusion is again supported by Surr et al (2017) which indicates that the government targets on 'number of staff trained' has led to a focus on quantity, rather than quality education.

A potential opportunity to improve training for ED staff is by looking to the "positive deviants". Examining the training pathways and core competencies of frailty nurses- who report high levels of confidence in their ability to interact with PWD and undertake comprehensive assessment- is likely to be an effective approach in identifying opportunities for improved training. Therefore, a critical appraisal to determine if there are opportunities to integrate some of the core competencies of geriatric nursing into general training opportunities for ED staff may be beneficial. This suggestion is supported by the research by Aldeen et al. (2014) which found that ED nurses reported increased confidence in their ability to care for PWD and older patients after receiving 82 hours geriatric specific training (both online and time spent on a 'care of older persons' ward). Furthermore, recognising the considerable skill of the frailty nurses, there may be opportunities to engage in 'on the spot' training and up skilling if ED staff regularly engage with frailty practitioners. This on the spot training was observed at Site Two, and made possible by explicit agreement between the frailty team and the ED management that part of the core function of the frailty staff is to provide education to ED staff. In contrast, at Site One, the frailty staff expressed a willingness to share knowledge, but felt they were 'outsiders' or 'visitors' in the department and therefore were not able to effectively engage in on the spot training. Explicitly defined roles and pre-defined training agreements between specialists and ED management may enable more effective 'on the spot' learning to take place.

10.3.6 Key messages

The safety implications of insufficient staffing, or inappropriate skills mix are clearly defined (Aiken et al., 2015; Berwick, 2013; Francis, 2013; Griffiths et al., 2014; Kane et al., 2007; Robinson et al., 2005). These risks apply to all patients, but have particular relevance for PWD who require additional support

while in the busy and disorientating ED. Effective dementia care is made possible by staffing which is sufficient in number, carried out by people with the correct skills to meet patient needs, and in working within models that enables staff to deliver high quality care. Escalation models must be designed to take account of the potential of PWD who present with 'low medical acuity' but whose presence impacts the ability of staff to provide good care. Increased presence of individuals who have an deliberately defined 'care focus'- such as care assistants or volunteers- may improve care without requiring additional registered nurses. The use of specialists can improve care provided they are used appropriately, and the risk of over reliance is recognised and addressed. Training and education have been recognised as major issues, and while change is slow on the national level, there are opportunities to improve care by providing skills based, hands on training in the workplace. However, it is important to note that improvements in care can only be realized if the staffing, training, and education are accompanied by a supportive organisational culture as "*sustained action and culture transformation is necessary for dementia care education to have a lasting effect on practice and achieve transformation of care culture*" (Dewing and Dijk, 2016, pg. 188).

10.3.7 Organisational culture

The organisational culture of an ED has an integral role in determining patients' experience of care. This is consistent with the broader literature on healthcare organisational and safety cultures which also strongly indicates that organizational culture is the primary driver of safety (Ruchlin, Dubbs, & Callahan, 2004) and therefore it plays an important role facilitating or hindering in the reduction of medical errors (Stock, McFadden, & Gowen, 2007) and improving care.

Several facets of organisational and safety culture were identified as being particularly relevant to the care of PWD. The facilitators included an open and positive safety culture, a culture of holistic or person centred care, and management of supply and demand through effective communication. In

contrast, the barriers include a tolerance of normalised deviance, silo working, a culture with excessive focus on the medical-technical aspects of care, a reactive approach to addressing challenges, and ineffective relationships with hospital and senior management. In many cases, these barriers and facilitators are reflective of different approaches to addressing the same circumstances; therefore, for brevity the section will progress through the following sections addressing the barriers and facilitators related to each.

1) Safety culture
2) Culture of care
    a. Medical-technical
    b. Person centered
3) Addressing challenges
    a. Proactive
    b. Reactive
    c. Relationship with hospital management

The following section offers a comparison between different organisational cultures that were identified at the two sites. In particular, some challenged aspects of the organisational and safety culture at Site One are highlighted, and it is possible these passages could be interpreted as critical. However, the intent is not to offer criticism or condemnation of Site One, it is to offer a comparative critique that highlights opportunities for learning and improvement.

The researcher is aware of a number of extenuating circumstances that have impacted the operations of Site One's ED, however, these cannot be fully described here without undue risk of identifying the site. The challenges have been identified to the onsite team at the hospital, and the researcher participated in a results-sharing session, which offered an opportunity to discuss and debrief the findings. The site has acknowledged the ongoing challenges with the organisational culture of the ED and has expressed a desire to work towards positive change in the future.

10.3.7.1 Safety culture

Safety culture is defined by the Health and Safety Commission of Great Britain as "*the product of individual and group values, attitudes, perceptions, competencies, and patterns of behaviour that determine the commitment to, and the style or proficiency of, an organisations health and safety management*" (Health and Safety Executive, 2005, Pg3). In the context of healthcare safety culture, a systematic review of the literature identified seven key elements of a safety culture, including

1) **Leadership:** Leaders acknowledge the healthcare environment is a high-risk environment and seek to align vision/mission, staff competency, and fiscal and human resources from the boardroom to the frontline.
2) **Teamwork**: A spirit of collegiality, collaboration, and cooperation exists among executives, staff, and independent practitioners. Relationships are open, safe, respectful, and flexible
3) **Evidence-based:** Patient care practices are based on evidence. Standardization to reduce variation occurs at every opportunity. Processes are designed to achieve high reliability.
4) **Communication**: An environment exists where an individual staff member, no matter what his or her job description, has the right and the responsibility to speak up on behalf of a patient
5) **Learning:** The hospital learns from its mistakes and seeks new opportunities for performance improvement. Learning is valued among all staff, including the medical staff.
6) **Just**: A culture that recognizes errors as system failures rather than individual failures and, at the same time, does not shrink from holding individuals accountable for their actions.
7) **Patient-centered:** Patient care is centered around the patient and family. The patient is not only an active participant in his own care, but also acts as a liaison between the hospital and the community.

(Sammer et al., 2010)

Participants identified a positive and open safety culture as a key facilitator of good care for PWD. In particular, they reported that providing effective, safe care was easier when; the potential risks of the ED for the PWD were recognised and addressed (*leadership*), the staff felt encouraged to raise their concerns about safety or wellbeing to others (*communication*) and when the views and needs of the patient and carer are actively considered during the care process (*patient centred*). Within this culture, responsibility for the wellbeing of all patients is shared between all staff, which promotes patient safety by ensuring input from the entire care team.

These attributes were notable at Site Two, where members of staff were observed- and self reported- sharing responsibility for supervising 'high risk' patients. In contrast, the staff at Site One reported that silo working is a frequent problem in their ED. Staff from Site One reported the constant strain of working under pressure had created an unwillingness to take on responsibilities that they felt where 'not theirs'. This was attributed to a fear they could be critiqued for poor performance during these extra responsibilities without recognition of the extenuating circumstance (*absence* of *justice*). Additionally, the staff from Site One reported that the constant pressures of poor flow and increasing numbers of patients had led to staff relying on sub-optimal practices (*Absence of evidence based practice).*

When these practices- such as getting other patients to watch the PWD while the nurse is called away-are used frequently, they become a normalised deviation, where staff occupy the margins of safety. Vaughn & Samudra (1996) used the term "normalised deviance" in their report on the Challenger Space Shuttle Disaster to describe how an organisation can continue with an unsafe practice despite increasing warnings of potential danger because the risk is rationalised, dismissed, or fails to cause immediate harm and is therefore accepted as a new norm. Dekker (2005) and Gawande (2011) describe normalised deviance as an insidious risk in healthcare, as unsafe practices

become the norm, and deviations from evidence are accepted. While the safety culture of an ED impacts all the patients, it is particularly important for PWD as they are already at a higher risk of experiencing an error or safety incident than other patient groups.

Closely linked to safety culture, is the organisational culture of care. The organisational culture- defined as the shared beliefs, values, norms of behaviour, routines, traditions etc. of a defined group (Parmelli et al., 2011) which has an integral role in determining the care environment, and defining which practices are prioritised. As reported in the phase two data, senior nursing staff in ED appear to play an integral role in determining what care is prioritized, what practices are enabled, and how patients and staff are treated. The senior nursing staff use their influence to direct resources to patients they feel have the greatest need, and either support, or chastise the staff nurses for spending time on tasks depending on their perceived worthiness. For example, if holistic care is perceived as worthwhile, the nurse in charge may offer to cover patients for staff nurses, which then frees the staff nurses to spend time with a distressed patient, or ensure that patients or relatives are given refreshments.

It is proposed that the staff attitudes on provision of hot drinks for patients reported here was a potential proxy measure of the priority given to person centered care. For many of the frailty and specialist nursing staff, provision of hot drinks- and food- in the ED is seen as an integral aspect of the therapeutic relationship. Additionally, food and drink are viewed as medical necessities that prevent dehydration, assist with orientation, provide comfort, and facilitate accurate assessment of function. However, amongst the ED staff nurses, hot drinks were typically considered a solely therapeutic intervention. At Site One, the value of providing a hot drink to a distressed, confused, patient was recognised, but not considered medically necessary. The ED staff shared the view that therapeutic interventions (like cups of tea) could, and should, only be provided when the department is flowing well. Some of the respondents from the site expressed their frustration that health care assistants have seemingly been diverted from their ‘expected role’ of providing comfort and care into more

medically oriented tasks. These staff felt their role as registered nurses and physicians was to provide skilled medical intervention. This view was reported during interviews by both staff and senior nurses. This is reflective of the findings of a systematic review on person centred practice in ED's by McConnell, McCance, & Melby (2016) who found a culture of 'medical-technical' primacy. They noted ED cultures traditionally focus on technology, medical status, and patient transition through the department. Additionally they found nurses emphasise their technical skills and ability to perform medical tasks when discussing their expertise and competencies, rather than discussing their caring abilities. Nydén, Petersson, & Nyström (2003) and Elmqvist & Frank (2015) equate this to a protection mechanism that ED nurses employ to prevent emotional burnout. Therefore, in order to remove this potential barrier to provision of person-centered care, it is essential to recognize, and react to, the emotional impact of caring experienced by ED nurses.

Interestingly the impact of supportive senior nurses to ensuring holistic care was notable at Site Two. Similar to Site One, the nurses at Site two viewed provision of hot drinks as primarily a therapeutic tool. However, unlike Site One, they felt maintaining the therapeutic relationship was an essential component of their nursing role- even when the department is busy. This could be explained in part by the emphasis placed on holistic care by the senior nursing staff, who frequently were observed assisting staff nurses, enabling them to step off the floor and get hot drinks for patients. Furthermore, the nurse in charge was sometimes observed sitting with a patient who was distressed or in need of supervision-enabling the staff nurses to continue with other responsibilities.

These practices were facilitated by the nurse in charge- and sometimes the matron- being physically present on the floor in ED - continually interacting with the more junior nurses. One observation here is that the placement of offices for senior nursing staff may influence the likelihood of such staff regularly interacting with staff nurses during their shift. At Site Two the nursing manager, senior sister, and nurse in charge office is directly attached to the ED, and these staff were observed working on a laptop in the main ED area. In contrast, the

matron and nursing manager office at Site One was located in another corridor, with two locked doors between the ED and the office. This had been recognised by site management as a barrier to substantive engagement at the time of data collection, and arrangements were being made to shift the matron's office to the observation ward which is directly adjacent to the ED. Interestingly, the staff nurses from Site One reported that they did not feel they had regular, positive interaction from senior nursing management, whereas those at Site Two felt they did. This suggests there may be a relationship between physical location of office and perceived openness of the relationship, which, if true, could have interesting implications for design of ED.

10.3.7.2 Addressing challenges

Organisational culture also impacts how the 'organisation' reacts to and addresses challenges. These organisational responses can have profound implications for team's ability to provide safe and effective care. Staff identified two different approaches to problem solving- proactive and reactive- and the differences between approaches were highlighted.

Staff from Site Two consistently described an open culture, which promoted the importance of escalating potential safety issues early to enable proactive intervention before crisis. This approach was reported by staff, and observed by the researcher. The staff felt this culture enabled them to care for PWD effectively, as they were confident support was available if required. Additionally, they felt, whenever possible, resources would be dedicated to supporting the ED if challenges such as surges in demand or a large number of PWD with high dependency needs were admitted to the department.

In contrast, the staff from Site One reported an approach to problem solving that was largely reactive. In this site, staff reported that the ED culture discouraged escalation, and reported that the only time support was offered from management was after the ED experienced a safety incident while in crisis. The staff felt senior management was reluctant to respond to requests for support due to the frequency of the site being on black status. They further felt

management only paid attention to concerns from ED in the aftermath of major safety incidents. This has led to culture which- they feel- does not encourage identification or escalation of potential issues. Thus, this dynamic has resulted in learned helplessness, and culturally embedded apathy to conditions that would typically result in escalation. In addition the staff feel the negativity within the organisational culture has lead to major staff turnover and subsequently increased use of bank/agency staff, which interferes with team working patterns and is likely to increases the risk. The association between staff turnover, burnout, and increased risk of poor care is supported by the work of Borneo, Helm, & Russell (2017).

One key difference identified by senior ED staff was the quality and content of communication between ED management and hospital (senior) management. Staff at Site Two reported regular, clear, and positive communication with the hospital bed managers and executives about resource needs. Additionally, they reported management frequently visited the ED to observe the working conditions and assess safety. The ED staff felt this close and positive relationship assisted them in providing effective care, as they are able to rapidly access resources and assistance when required. Sutcliffe et al (2004) proposed that openness and quality of communication are key to improving patient safety, but cautioned that these are frequently overlooked in favour of concerns about hierarchy and power. This project supports the conclusion that open and effective communication between ED staff and management can have a positive impact on ability to provide effective care for PWD.

In contrast, the managers from Site One reported a strained relationship with their seniors. They felt that hospital management had adopted a “sledgehammer” mentality to problem solving in ED, where minimal assistance is offered preceding or during a crisis, but micromanagement is implemented after a crisis. This had led to a hesitancy to report challenges, and indeed near misses- also reported by Reason (2011)- which contributed to strained relations between the ED staff and hospital management. The strained relationship

between front line staff and management was evident in the “us” vs “them” language which was used by ED staff when describing their interactions with management (see pages 207-8).

This dynamic is discussed by Dekker (2005) who suggests tensions arise when managers try to improve care by implementing increasingly prescriptive guidance, and then try to enforce those best practices by ‘legislating compliance’. The problem with this approach, according to Dekker, is that these guidelines are generally only appropriate to address a simple- cause and effect-relationship, and are therefore fundamentally inappropriate to address challenges in complex systems- such as EDs- especially when the patient is similarly complex. Dekker writes “ *…complex systems are contextual and contingent, varying with time, technology and social clinical composition…”* and therefore “*efforts to impose a single norm onto complex practice are, not surprisingly, characterised as colonial patronage*” (Pg. 222) which is to say, they are entirely unwelcomed. At Site One this appeared to manifest in attitudes towards adaptations in practice that originated from management. Staff reported that these proposals are either viewed contemptuously, implemented only under duress, or ignored outright. When these unwelcome interventions are enforced the staff find “workarounds” to avoid what they feel is unnecessary and ill conceived interference (Watcher and Pronovost, 2009), which can increase the likelihood of clinical error.

Moreover, at Site One, these ongoing tensions between management and ED staff had created a distinct micro culture, which is at odds with the strategic vision and intended organisational culture championed by management. According to Skar et al (2015) it is common for an ED to have a separate micro culture from the rest of the hospital as a result of the unique demands of the environment and the relationships of staff. Skar et al further note these micro-cultures can be challenging to transform, as attempts to implement change from ‘the outside’ are viewed as unwelcomed and generally perceived as imposed by people lacking adequate understanding of context. In

this scenario, a new approach to problem solving is required to interrupt the currently dysfunctional relationship between ED and management.

Asset based problem solving- as described in the methodology chapter- involves the identification of a mutually desired outcome, and then considers what assets exist within the organisation that could be leveraged to achieve that outcome (McClean, 2012). At its core, asset based problem-solving centers on the belief that the knowledge and skills required to create and sustain effective change can be found within the organisation. The potential benefit of using this approach is that it would actively involve ED staff in finding solutions, which could avoid the tension associated with to perceived external micromanagement. For Site One, addressing this challenging dynamic within the organisational culture, to remove communication barriers, and facilitate more effective team working with management, will be absolutely essential to improving the care of all patients – and especially PWD.

In conclusion, the organisational culture of an ED plays an essential role in facilitating, but can also hinder, the provision of effective care. The importance of a positive organisational culture is particularly relevant for PWD as organisational culture is a primary driver of safety (Stock et al., 2007) and PWD experience higher levels of risk in the ED as a result of their dementia. This view is supported by McCormack et al (2011) who state that it is the culture of a care environment- not the processes of care- that influence patients and staff most. Therefore improving care requires sustained commitment to changing organisational culture. This is especially true for older people and PWD who report that the quality of communication and experience of interactions are central to forming their experience of care.

Ensuring the organisational culture actively supports and enables staff to provide a positive experience of care in ED can have important implications for the rest of the inpatient stay- both with regards to safety and satisfaction with care. For example, Jurgens et al (2012) describes a cycle of discontent that many carers of PWD in acute care describe. This cycle begins with a carer having expectations of the quality or type of care their relative should receive.

When these expectations are unmet- for example due to a lack of person centered care in the ED- the carers can become hyper vigilant or suspicious which leads to monitoring of staff for ongoing evidence of poor care. This can then lead to conflict or challenges with the staff, which complicates care processes. This “cycle of discontent” can begin as early as presentation to the ED, and therefore ensuring the organisational culture facilitates a good experience of care is essential to establish the conditions for a positive and successful inpatient stay.

10.3.8 Key messages

This section has discussed some of the barriers and facilitators of good dementia care in the ED. The first sub-section discussed the role of communication in supporting, or hindering good care- focusing in particular on the impact of IT system integration- or lack thereof- and the contributions of family. The second sub-section discussed the physical environment with a particular focus on the impact of excess demand creating crowding. Additionally, this section discussed how the physical environment of ED can either support, or interfere with staffs ability to provide safe and dignified care- suggesting a separate older persons ED may be an effective means of addressing the challenge of unsuitable environment. The third sub-section discussed the impact of staffing levels, focusing on safe staffing and the challenge of workforce planning in the ED. The role of specialist staff in supporting good care was also discussed, with a caveat that overreliance on specialists can become a barrier to good care if it creates dependency. The current deficiencies in dementia training were highlighted, with staff requesting hands on, skills or competencies based training. The final sub-section discusses the essential role organisational culture plays in supporting or hindering provision of good dementia care. In particular, it promotes the importance of creating an organisational culture that promotes open communication, a positive safety culture, and supports person-centered care.

10.4 Recommendations for a Dementia Friendly emergency department

The final aim of this research was to outline the structural and procedural changes that would be required to enable more consistent provision of dementia friendly care in ED's in the NHS. To address this aim, existing recommendations from the literature are presented, and supplemented with additional insights from this project regarding the barriers and facilitators of good care.

For the purposes of clarity, the existing guidance used here is the US Geriatric ED guidelines (2013) as they are the most comprehensive and prescriptive. The Silverbook (Banerjee et al., 2012) was considered as a comparative framework, but the multi-location, multi-system presentation format does not offer the level of detail in the ED setting as the Geriatric ED guidelines. As with other areas of this thesis, these recommendations are presented using Donabedians S-P-O model as a framework. Each section of recommendations is presented in two parts, the first signposting to existing recommendations found in literature, and the second presenting a commentary on those guidelines and offering further recommendations emerging from this research.

10.4.1 Structures

Structures includes any fixed input into care that impact the context of care delivery including facilities, equipment, personnel, and organisational policies (Donabedian, 2003). For the purposes of this project, structures include the physical environment, equipment and supplies, staffing and human resources, and training.

10.4.1.1 Physical environment

Existing recommendations on environmental adaptation from the Geriatric ED guidelines can be found in the guidelines (American College of Emergency Physicians et al., 2013, pg 13-15). These recommendations form a fairly comprehensive and prescriptive outline of the physical environment requirements for Geriatric ED's. Based on this research, additional recommendations are proposed which are specific to dementia friendly ED's.

Firstly, alongside the recommendation that physical structures should promote safety, comfort, mobility, memory and sensory perception; environmental design also should ensure preservation of patients dignity and aim to remove environmental features which act a barrier to staff ability to provide effective care. A safe, dignified, and enabling environment ensures; easy access to washrooms for patients and carers, kitchen or canteen facilities for patients, carers, and staff, and ensures the physical environment enables carers to stay comfortably with the PWD. Therefore, in addition to the Geriatric ED guidance, the following is proposed;

- The physical environment of the emergency department should support the maintenance of independent function, preserve patient dignity, and enable staff to provide care without environmental barriers
- Staff should have easy access to a kitchen enable easier provision of food and hot drinks to patients
- Environmental design should be cognizant of the (potential) need for carers to stay with a PWD and provide adequate space and equipment to facilitate this *i.e. space for chairs by the bedside, or a cot to stay overnight.*
- If an entirely separate area is not possible, a small section of the ED which is maintained as a quiet, or quieter space would be beneficial.

10.4.1.2 Equipment and supplies

Existing recommendations from the Geriatric ED guidelines can be found in the GERI-ED report (American College of Emergency Physicians et al., 2013, pg 13). As with the environment, the recommendations here offer comprehensive guidance on the furniture and equipment that can improve the quality and safety of care for older people.

The findings of this research support the recommendations proposed in the Geriatric ED guidelines, in particular the suggestion that alternatives to hospital trolleys or beds should be offered where possible. Both staff and carers reported that it can be difficult to encourage PWD to stay on a bed, and the

benefits of reclining chairs for reducing pain and improving satisfaction in older ED patients is indicated by Wilber et al (2005)

What is missing from these recommendations is equipment or supplies that are specific to the need for occupation in the ED, signposting and reorientation, and supplies which can address concerns specific to PWD i.e. different flatware to encourage eating and drinking.

- Materials to provide occupation for people with dementia- for example, fiddlemitts, newspapers, basic art supplies, picture albums, music etc.
- Large, easy to read clocks.
- Large, visible calendars
- Large whiteboards for information sharing in each cubical or room, or small whiteboards shared with patients/ carers
- Flatware in bright colours to improve nutrition and hydration
- Cups, beakers, and straws to assist with hydration
- Fluid thickener

10.4.1.3 Staffing and human resources

Existing recommendations on staffing can be found in the Geriatric ED guidelines (American College of Emergency Physicians et al., 2013, pg 4-6). These guidelines are arguably overly weighted in focus on physician input- which is likely reflective of the design cohort who were primarily physicians. In particular, the explicit reference to type and hours of continuing professional development for physicians when compared to the recommendation that nurses be 'encouraged to participate' in geriatric education, is concerning. This project found that interactions with staff are strongly associated with satisfaction and experience of care, and nurses have considerably more contact with patients than doctors in a majority of cases. Therefore, an additional focus on nursing staff education is required to ensure the ED is dementia friendly. Additionally, the Geriatric ED guidelines only discuss managerial and staff level positions, neglecting to provide explicit reference to levels of seniority within the various

positions. This research highlighted the importance of senior nursing staff on the floor to provide role modelling, mentorship, and rapid support. Therefore, in addition to the existing guidance on staffing, the following is proposed;

- Each ED should have at least one Matron or Band 7 nurse who has received formal training in Geriatrics- including specific training on dementia. (For details on training, see section on training below)
- That anyone taking a 'nurse in charge' role should have training in geriatrics and approaches to dementia care.
- Each hospital should have a dedicated team of 'dementia support workers' whose primary responsibility is to provide care and companionship to support the wellbeing of PWD and carers who support them- patients in ED should have preferential access to these workers.
- That safe staffing levels are calculated with due consideration of the additional needs which PWD may have, and that surge planning takes this into account
- That the value of healthcare assistants for PWD be reflected in staffing models, and that due consideration is given to the importance of balancing numbers of care assistants and registered nurses.

10.4.1.4 Training

The geriatric ED guidelines propose recommendations training and education (American College of Emergency Physicians et al., 2013, pg 8-10). These recommendations offer an excellent starting point for increasing the skill of medical assessment of older people, increasing awareness of common geriatric issues, and recognizing the risk of atypical presentation of disease in older people. It is heartening to see the value placed on inter-disciplinary learning, competency based learning, and a recommendation for the use of mixed and multiple methods for education. Additionally, the commitment to

extending education to a broad range of stakeholders including patients, carers, and paramedics is a positive step towards 'whole systems thinking' and demonstrating commitment to involving patients and carers in managing their own health.

This research indicates staff desire skills based, hands on, scenario or case based learning opportunities, and the geriatric ED recommendations reflect that desire. What is missing from the recommendations is training on communication skills and approaches to deescalate distressed or agitated behaviours. Additionally, these recommendations focus exclusively on formal training opportunities, whereas participants in this research noted that informal mentorship opportunities and on the job training were often a key avenue of learning for ED staff. Therefore, in addition to the above guidance, the following is recommended;

- Any person holding a Medical Director, Director of Nursing, or Matron position in ED should have tier three dementia training, as defined by Health Education England. In addition, they should have some formal training in geriatrics.
- Any person holding a 'nurse in charge' or 'consultant' role in ED should have-at minimum- Tier Two training in dementia as defined by Health Education England. Preferably, these staff should have Tier Three dementia training reflecting their leadership role in the department.
- All other clinical staff, including health care assistants, staff nurses, physicians, and allied health professionals who work in ED should have Tier Two dementia training as they are likely to interact weekly, if not daily with PWD in clinical settings.
- ED's should consider developing a mentorship program where junior or newly qualified nurses can partner with senior nurses, dementia support workers, or older peoples nursing specialists and engage in peer-to-peer learning.
- Simulation or role-play training, especially in soft skills should be considered to enable staff to learn in realistic, but non-pressurised

environments. ED's could consider asking people living with dementia to participate in training sessions as 'patients'.

- Communication skills, de-escalation of distressed behaviours, and relationship building should be core elements of workplace education and training programs.

10.4.2 Processes

Processes are defined as the actions that make up 'healthcare' at the point of delivery (Donabedian, 2003). For the full definition of processes- including differentiation between technical and interpersonal processes, please see pages 137-138 of this thesis. In the Geriatric ED guidelines, the recommendations on technical processes are designed to increase the proportion of older patients who are receiving established 'best practice' assessment in ED. This is evidenced by the focus on clinical protocols found in existing guidance. A number of technical processes are recommended in the Geriatric ED guidelines (American College of Emergency Physicians et al., 2013, pg 15-35).

This research supports the recommendation that there would be benefits to adding geriatric specific guidelines, protocols, and processes in ED to address the current gaps in skills and knowledge. Adopting a more protocolized approach to care for PWD and older people is one way to address the current variation in service provision that exists in the UK. Additionally, the use of protocols and other standardized measures could reinforce the principle that care of PWD is everyone's responsibility in ED. In his book, The Checklist Manifesto, Gawande (2011) discussed the success of use of protocols and checklists for improving clinical outcomes, and noted that the use of a protocol meant every member of the clinical team has equal ownership of, and responsibility for, the tasks laid out in that checklist. Gaps in knowledge on 'best practice' for geriatric care were identified as a barrier to provision of good care in both the literature and this research, so implementing protocols may be an effective means of ensuring more patients receive best practice care.

However, it is essential to remember that while implementing protocols or standards can potentially improve clinical outcomes, the elements of care which are most strongly associated with satisfaction and perception of dementia friendliness relate to how care is delivered, not what care is delivered. Furthermore, excessive focus on 'standardisation' can frustrate staff, and at times interfere with development of relationships if ' task completion' is given higher priority than provision of person centered care within the organisational culture.

Therefore, an ED culture should give equal prominence to person centered care and authentic partnerships with carers, as it does to the use of standardised protocols. Furthermore, wherever appropriate, patients and carers should be encouraged and supported to comment on their care and be involved in decision-making, upholding the dignity and personhood of these parties. Measuring, quantifying, and changing organisational culture can be challenging. However, there are a number of tools available which can support organisations wanting to assess their culture including the 'Culture of Care Barometer" (Rafferty, Philippou, & Fitzpatrick, 2015) and "Measuring and Assessing Organisational Culture in the NHS guidance (Mannion, 2008). The commitment to ensuring person centred approaches are embedded in practice can be demonstrated by allocating resources- both financial and human- towards dedicated 'champion' or 'link' roles. Therefore, in addition to the above technical process protocols, the following is recommended;

- Annual audit of organisational and safety culture in the ED using a predefined assessment tool such as the "Culture of Care Barometer" (Rafferty et al., 2015) or "Measuring and Assessing Organisational Culture in the NHS (Mannion, 2008)
- Define- with PWD and carers- proxy audit measures for dignity and person centeredness in the ED. For example, how many patients have their preferred name recorded on notes? How many patients have their usual method of toileting recorded and upheld? How many patients or carers are offered food or drinks in the ED? Do patients feel respected

while in ED? Do patients and carers feel there was effective communication in ED? Etc.

- Ensure any ‘link roles’ or ‘champion’ roles for older people or PWD in ED are appropriately resourced.

10.4.3 Outcomes

Outcomes are the effect of healthcare on a given population including promotion of recovery, functional restoration of ability, survival and patient satisfaction (Donabedian, 2003). Measuring outcomes is a means of tracking impact and assessing the added value of implementing geriatric ED interventions. A full list of outcome measures is proposed in the Geriatric ED guidelines (American College of Emergency Physicians et al., 2013 pg 10-13).

These proposed outcome measures focus on health systems performance or biomedical outcomes relating to ED attendance. This type of outcome measures is useful if the goal is to gather empirical evidence of differences between ‘standard care’ and ‘geriatric ED care’. Given the current lack of empirical evidence it is understandable that these outcome measures are prioritized. However, given that interpersonal aspects of care are the key determinant of satisfaction for PWD, outcome measures which focus on the patient experience would be more likely to demonstrate actual impact. There is a need for additional research on how to identify and embed patient defined and reported outcome measures as a means of assessing impact. Assessing intervention impact in this setting requires a nuanced, sensitive approach that can accurately assess implementation fidelity and determine correlation between multi-component interventions and outcome.

Additional research, and patient and public involvement is required to define outcome measures for patients and carers which should be measured. Furthermore, given the importance of disease specific knowledge to patients and carers, and the current gap in skills based training identified by staff, it is recommended that future assessments consider staff training as a measureable outcome. However, rather than focusing on numbers of staff trained, it would be

valuable to conduct assessments as pre-post training evaluations which measure changes in willingness to care, attitudes towards dementia, and confidence. Therefore, in addition to the outcome measures proposed by the geriatric ED guidelines, the following is recommended:

- Consult patients and carers to determine outcome and quality metrics that reflect experiences of care as well as medical or health systems outcomes of care.
- Evaluate impact using nuanced approaches- such as realist evaluation (Pawson & Tilley, 2001)- using evaluation tools that are appropriate for the complexity of the patient needs and environment.
- Embed human factors, systems based thinking in impact assessment- assessment of a complex intervention should not be undertaken using a simple 'cause and effect" model.
- Evaluate training not by quantity of staff trained, but rather by assessing changes in willingness to care, attitude change, and confidence.

10.5 Limitations of the study

10.5.1 Involvement of people with dementia

One of the objectives here was to include a substantive, representative contribution from PWD. Recruitment was a major challenge throughout phases one and two, and as such, this aspiration was achieved only in part. Additionally, within the survey, it was not specified whether the self identified PWD were living in the community or in formal care settings, meaning there was a potential that these data would over-represent individuals living in the community, fail to capture experiences of people living in care homes, and therefore not be fully reflective of a continuum of experiences. Furthermore, as a result of the sample size, it was not possible to confidently differentiate by respondent type in the statistical analysis - which may have identified important differences in perspective.

Additionally, recruitment of PWD and carer dyads for phase two of the research was a considerable challenge. While this ultimately resulted in a change to the research protocol, there are important lessons which can be drawn from this experience for future research. Firstly, the challenge of recruiting from the ED became clear over the course of the project. In particular, it was challenging to identify, consent, and follow up with patients in the ED setting as the patients move through the department rapidly. Additionally, the cooling off period caused a number of patients with short stays in hospital to become lost to follow up. Lastly, the decision to interview care dyads after discharge –as opposed to while they were resident on wards- meant there were a number of participants who either failed to meet the inclusion criteria due to extended length of stay, or felt they could not comment on the experience of being in ED as too much time had elapsed. In future, researchers could consider the potential for interviewing patients in alternative settings, or using different approaches to gather data to maximize opportunities for participation.

While these limitations may have an impact on what conclusions can be drawn from the data, the value added by the contributions of PWD cannot be over-stated. This is a traditionally hard to reach group, and the involvement of PWD –including those with advanced dementia in care homes- is an important first step towards more inclusive dementia care research.

10.5.2 Phase One.

On reflection, a different model of data collection, which utilized face-to-face survey completion- possible in group settings- rather internet-facilitated (or postal) survey completion, may have been more effective in eliciting the views of PWD. However, a balance had to be sought between time constraints and the requirement to collect a reasonable volume of geographically diverse data

The survey tool that was used to gather data was not previously validated however, it was specifically co-designed for this research. Accepting the use of non-validated surveys obviously impacts on the validity and reliability of findings; however, the rigorous consultation and consensus process for developing the

survey made a significant contribution to the face and content validity of the tool. The development was further enhanced by a rigorous process of expert review, and reliability testing (See Chapter Five). In future, the survey would benefit from additional testing to measure convergent or discriminant validity, and predictive validity. Additionally, the survey would benefit from completion of factor analysis and calculation of Cronbach's Alpha to assess scale reliability and internal consistency (Pallant, 2016) as per common convention on validating survey instruments (Ping, 2004).

The inability to track the response rate of online surveys- or determine how many of the paper surveys actually reached the intended participant population- is a further limitation of this study and is a threat to rigour.

The statistical testing here can only demonstrate associations and correlations, not prove causation. While the strength of the correlation and statistical significance of the findings suggests there is potentially a causal relationship, additional research is required before a causal relationship can be declared confidently. A more confident prediction of causation would likely require a form of regression analysis.

10.5.3 Phase Two

The major limitation of phase two of the study is that it was conducted in a single health economy as this can have important implications for generalizability and transferability. Generalizability is always a contested issue in qualitative research, as the limited sample sizes utilized for most qualitative research do not easily lend themselves to generalizability. While the sample size for this research was relatively large for a qualitative study, and involved a variety of staff from multiple sites, there are still potential limitations in representativeness. In particular, the UK is a multicultural and diverse country, and this study was centered in an area where patients are predominantly Caucasian, born in Britain, and speak English as a first language. Conducting this research in a more ethnically diverse setting could have potentially identified additional, or different barriers to the delivery of good care for PWD in ED.

However, it can be argued that the primacy of generalizability as a means of assessing quality in research is associated with positivist scientific view, which is out of step with some social science perspectives. Instead, transferability may be the more appropriate measure of quality (Sandelowski, 2000). The detailed explanation of method, sample, and findings, should be sufficient for fellow researchers to examine the research and determine if they feel the findings are transferrable to their context. The missing information on the context of service delivery and management at Site One (which, as noted above, had a considerable impact on the organisational culture) could be a potential barrier to transferability. However, the need to protect the privacy of the site must take precedence.

Additionally, the researcher's background- non-clinical, and not an NHS employee- could have had an influence on the nature and type of information that was sought by the researcher or shared by respondents. The researcher's background in politics and patient safety/quality improvement meant the focus remained primarily on health systems and patient experience. Critics may argue that a lack of experience as a care provider in ED means the researcher would be unable to fully understand the context of the setting. However, the multiple and mixed methods design maximized potential for familiarisation with the operational context. Additionally, the lack of previous clinical experience is arguable a potential strength of the research as insider knowledge can sometimes cause a lack of objectivity.

Finally, having a single researcher collect, organize and analyze the data introduces a significant risk of bias in the findings. The steps taken to reduce bias- including the use of a reflective journal and structured data collection instruments - have been detailed in Chapter seven. Single researcher bias is an accepted risk of qualitative research that does not involve a research team, but still must be acknowledged as a potential limitation.

10.6 Implications and recommendations

This study has implications for research, practice and policy. These are presented in bullet form.

10.6.1 Research: design and method

- If a future researcher were to use the same survey instrument to replicate this study on a larger scale it would be beneficial to apply for Health Research Authority approval that would allow recruitment directly from ED.
- For future survey completion with this target population, it may be more effective to work in partnership with organisations that have regular contact with PWD to run group sessions enabling individuals to fill in surveys with support; or one to one with a researcher/ research assistant present.
- Future researchers wanting to explore ED experiences of PWD and carers should consider recruiting patients on wards and collecting data while the care dyads are in the hospital to prevent potential loss to follow up. There are ethical imperatives to ensure an adequate balance between the need for data collection and the wellbeing of participants.

10.6.1.1 Future research

There is a limited body of empirical evidence on the effectiveness of interventions designed to improve ED care for older people and PWD. Given demographic projections, this issue will become increasingly important and therefore should be a priority for research. Several potential research questions for further investigation emerge from this study, including

- Further exploration to determine what is important to people with dementia and their caregivers when they access care in ED?
    - How can we ensure these priorities are embedded in practice and evaluated as part of impact assessment?

    - What positive outcomes- both medical and social- can be achieved by implementing dementia friendly environments, person centered care processes, and skills based training programs in ED?
        - What is the cost effectiveness of these interventions?
    - If multiple adaptations are implemented at the same time, which interventions are most successful in improving long term outcomes for PWD and improving satisfaction?
        - How do we measure the relative impact of each intervention?
- Given the complexity of this topic (geriatric medicine and cognitive impairment), and environment (ED), further investigations may be well suited to a realist evaluation design, as it will require pragmatic and realistic assessment determine overall impact.

10.6.2 Practice

The most important implications for practice are the potential for improving services by integrating the priorities of PWD and carers into service delivery in ED; and the discrete lessons for patient safety. The identification of these priorities has been an important first step in aligning service provision with the needs of this patient group.

- This research again reiterates the importance of authentic person centred approaches to care for PWD- it has been highlighted as a priority in a variety of other settings, and this project confirms it is equally relevant and desirable in the ED setting.
    - Staff report a desire and willingness to provide person centered care for PWD, but are hampered by 1) lack of training, and 2) lack of time and space
        - Providing additional, skills based training, which focuses on the practical skills required by staff to effectively interact and engage with PWD in the ED setting will improve confidence

    - Adaptation to the environment- including the potential for developing entirely separate ED spaces for older people- can remove some of the environmental barriers which prevent staff from providing person centered care
- Failure to take the priorities of PWD and carers into account when considering service redesign risks creating change without actually facilitating improvement.
- This research demonstrates the contribution of organisational culture to willingness to escalate potential safety issues in ED- ED managers can, and should, assess the organisational culture to ensure it promotes a culture of shared responsibility for patient safety, and that good relationships with senior managers are maintained.

10.6.3 Policy.

At the policy and strategic level there are a variety of implications from this research. These can be divided into institutional policy level and national or regional strategic policy levels.

10.6.3.1 Institutional policy

Carer involvement

- Institutional policies that support and enable more involvement from carers should be encouraged.
    - Any hospital that does not have an existing carers policy should implement one promptly. If a hospital does have a carer's policy, it should ensure the policy is embedded in ED, working as intended, and achieving the desired outcomes. It is not enough to simply allow carers to be there, they must be provided with some level of physical and social support, which enable them to do so comfortably. Carer's policies must be supported by organisational

culture, which embraces the value of involving carers in the care of PWD in ED and beyond.

Data sharing

- Hospitals should critically appraise their data sharing policies with local services such as GP's, nursing homes, and community care providers.
- Incompatibilities should be addressed at an institutional level to facilitate more effective flow of information.
- Promotion of 'opt in' schemes to enable data sharing should be undertaken in both acute and community settings.
- As an interim measure the hospitals may consider advocating increased use of facilitated information transfer tools such as RESPECT forms, This Is Me, or the Red Bag Program.

Escalation policies for crowding or unsafe situations in ED

- Hospitals should ensure they have clearly defined escalation policies that explicitly address the potential for patients having needs in excess of what may be anticipated given volume or acuity.
- All ED staff, not just seniors, should be aware of this escalation policy.
- Organisational culture must encourage and support appropriate and early escalation of potentially unsafe conditions in the ED- failing to respond to requests for help risk the potential of normalising unsafe practice and encouraging learned apathy to patient safety risks.

Specialist staff

- The ED would benefit from establishing explicit guidelines on the role and function of specialist staff within the ED
- Ensuring specialist staff are used as intended (i.e. differentiating between those whose primary function is companionship and care versus skilled assessment) will maximize potential positive impacts.
- Assess when the need for specialist staff support is greatest, and align working patterns of specialists to meet those needs

Training

- Hospitals should develop an on-the-job training program that is skills based.
- Hospitals could consider asking members of their frailty or geriatrics team to assist with developing content of these training programs to ensure core competencies in communication, de-escalation and clinical assessment are addressed.
- Hospital managers should ensure training times are protected to ensure maximum staff engagement.
- When measuring impact assessments should focus on changes in attitude, knowledge and confidence rather than on numbers of staff trained.

10.6.3.2 National or Regional Policies

- Local regulatory or commissioning bodies could support hospitals to provide better dementia care by creating CQUINS that are associated with elements of the care experience identified as important by PWD and carers.
- Addressing the persistent shortfall of staff through improved recruitment and retention will likely improve morale and support staff to deliver better dementia care in ED.
- Clearly defined safe staffing levels for ED would assist managers to create business cases for use of temporary staff in times of additional pressures.
    - If possible, safe-staffing ratios should be stratified by age group, and or patient acuity, in recognition that certain patient groups require more nursing input than others.
    - Health Education England should consider creating a co-designed core competencies based curriculum (Conroy et al., 2016; Hogan et al., 2010) when it next revises its dementia care programme to address the skills gap.

- Future workforce planning should take into account the holistic needs of PWD and ensure staffing and training models are appropriate to the needs of this increasing patient population.

These recommendations have emerged from literature and exploration of the current experiences of receiving and providing care. It is evident that clear communication, effective staffing models, the physical environment, and organisational culture all play key roles in enabling the provision of dementia friendly care in ED.

Conclusions

The current 'medical model' of disease focused, episodic, emergency care is unlikely to meet the needs of older patients-especially those with cognitive impairments. The complex needs of geriatric patients and PWD would appear to be fundamentally misaligned with the rapid triage systems and intervention based focus of a typical ED. This misalignment of patient needs and service provision is likely to drive widespread dissatisfaction with ED care; leaving patients and carers feeling anxious, overwhelmed, and abandoned. As the population ages, and increasing numbers of PWD require care in ED, it is essential to ensure emergency care is safe and of high quality for the inevitable growth in this patient group. Given the existing and multiple risks to safety, alongside a substandard patient experience, more radical changes in the health system- including entirely separate geriatric emergency departments- may be warranted.

This research used mixed, complementary methods in a sequential design to untangle complex challenges in health care. Each phase of the research informed the subsequent research activities, strengthening the quality of the data and underpinning the key messages which followed. The human factors approach to patient safety, which encourages 'whole systems' thinking to identify sources of risk and opportunities for safety across the entire system has provided a pragmatic theoretical base. This approach has also facilitated a critical appraisal of the various interactions between individual (patient, carer, and staff) and the broader 'system' in which they exist to identify risk and proffer solutions. This work has importantly demonstrated that co-designing surveys with people with dementia and family carers is both feasible and justifiable, and that using systematic processes of co-design can produce a credible instrument for exploring experiences, perceptions, attitudes, and needs of this patient population

There are a number of barriers which may affect the healthcare team's ability to provide effective dementia care- including poor integration of communication systems which impacts quality and continuity of care, physical

environments which cause PWD distress and increase the burden of care for staff, and difficulties with staff recruitment, retention and training. These systemic challenges both give rise to and exacerbate poor organisational and safety cultures, as a consequence care priorities become blurred and staff-patient interactions become less person-centred.

This work has limitations but is an important first step in identifying the priorities of care for PWD, and identified some of the organisational and systematic facilitators which can support staff in providing person centered, safe and holistic, emergency care. The challenges reported here, while daunting, cannot be allowed to supersede the need for reform to ensure safe and effective care for some of our most vulnerable patients.

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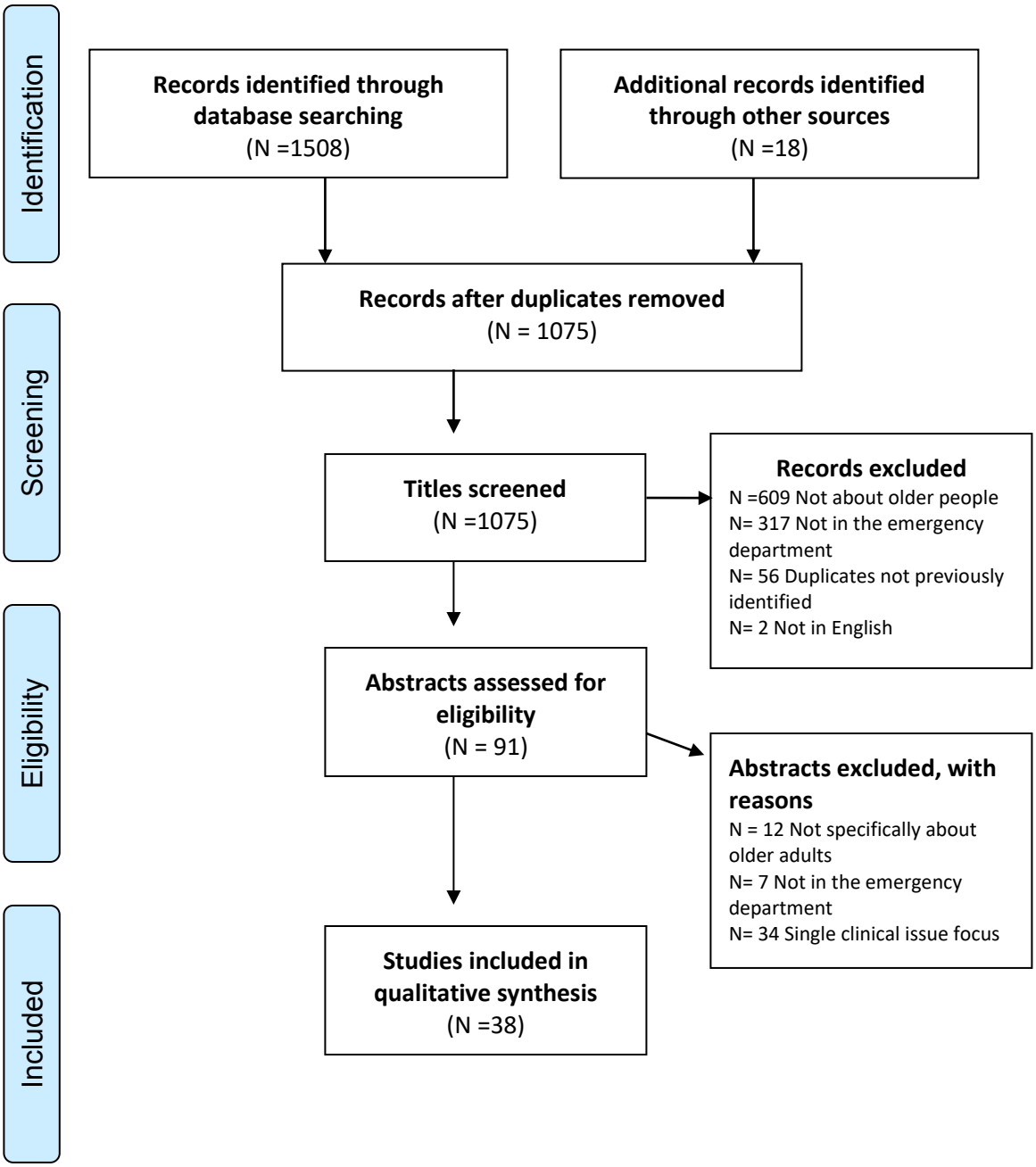
Appendices

Appendix one: PRISMA Diagram



Appendix two: Example search strategy- MEDLINE

Search
S1:Geriatrics (Explode) (28,733)
S2: Geriatric (94,381)
S3: senior (47,491)
S4: Aged (Explode) (2,824,123)
S5: Frail elderly (explode) (9,545)
S6: older adult (6,060)
S7: S1OR S2 OR S3 OR S4 (2,907,878)

S8: Emergency service: Hospital (explode) (58,270)
S9: Emergency medicine (explode) (12,273)
S10: Emergency nursing (explode) (6,681)
S11: Emergency department (keyword) (74,974)
S12: Trauma centers (explode) (9,067)
S13: Accident and emergency (Keyword) (5,637)
S14: Casualty (keyword)
S15: Emergency room (keyword)
S16: S8 OR S9 OR S10 OR S11 OR s12 OR S13 OR S14 OR S15 (142,253)

S17: S7 AND S16 (29,917)

Limit to: Published after 1997- 26,493
Limited to: English language – 24,767

S18: Policy (expand)
S:19 S7 AND S16 AND S18 Limits in place post 1997 and English language (111)

S20: Health planning guidelines (3,993)

S21: S19 AND S20 (220

S22: Health Planning guidelines (explode)

S23: S20 OR S22

S24: S19 AND S23 (116)

Appendix three: Literature Summary Table

Source	Country	Type and Evidence level	Participants	Sample size	Key findings or key messages
Aldeen et al (2014)[8]	USA	Journal Article **Level 4** Quasi-Experimental- review of clinical outcomes pre and post implementation	ED Nurses participate in training, patients in ED over 65, with ISAR score over 2 are eligible for inclusion in trial	4 nurses under-going specialist training at one site 408 patients received assess-ment by these specially trained nurses	• Nurses undertook 82 hours GEDI training. • Patients eligible for GERI-ED nurse screening if they have ISAR over 2 and arrive between 9am-8pm M-F. • Over study period 2,124 patients were potentially eligible, 408 consultations occurred. • Employing nurses who have receive a 3 month training course on in geriatrics increases likelihood of comprehensive assessment and may be associated with reduced likelihood of inpatient admission. • Limitations include limited number of hours that geriatric trained nurses work. • Slight increase in length of time patients spend in ED if reviewed by GERI-ED nurse .
American College of Emergency Physicians et al (2013)	USA	Guideline **Level 1** Guideline based on systematic review	N/A	N/A	• guidelines, experts in geriatric research or emergency medicine. • Split into two working groups- 'structural and staffing' and 'clinical and technical' • 40 recommendations based on review of the literature and expert consensus • Method used for literature review not defined • Recommendations on staffing, transitions of care, education, quality improvement, equipment & supplies, and policies,

* as defined by Polit, D. F., & Beck, C. T. (2008). *Nursing research: Generating and assessing evidence for nursing practice*. Lippincott Williams & Wilkins.

					procedures & protocols
American Geriatrics Society (2017)*	USA	Announcement **Level 7** Announcement	N/A	N/A	Announces the forthcoming geriatric ED accreditation process
AminzadeH &Dalziel (2002)	Canada	Journal Article **Level 1** Systematic Literature review of RCT's with meta-analysis	N/A	24 studies included in review	• Reports the patterns and outcomes of ED use by older adults • Finds that older adults use emergency services at a higher rate, their visits have a greater level of urgency, they have longer stays in the emergency department, they are more likely to be admitted or to have repeat ED visits, and they experience higher rates of adverse health outcomes after discharge. • Concludes current disease-oriented and episodic models of emergency care do not adequately respond to the complex care needs of frail older patients • Suggests additional research is required as traditional "outcome" measures may be inappropriate for older people, and notes limitation that many studies exclude people living in care homes or living with cognitive impairment
Andrews and Christie (2009)	Scotland	Journal Feature **Level 7** Review and commentary of clinical best practice guidelines by experts	N/A	N/A	• Discussion of the six recommendations for 'best practice care' of people with dementia who attend ED in Scotland • Psychological assessment to assess for confusion- for older people • Staff require training in effective approaches to dementia care • A 'flag system' should be used to identify patients requiring additional care • Admissions should be avoided where possible • Staff attitudes to dementia should be changed to reduce intervention • Patients with dementia should have minimal care

					transitions
Australasian College for Emergency Medicine (2015)	Australia	Policy **Level 7** Policy statement, endorsed by expert committee, no reference to design process	N/A	N/A	• Addresses the general entitlements of older people in ED- including the right to be involved in care and respect for dignity and autonomy • Also covers clinical policies, administrative approaches, ED design, education and training and transitional communication policies. • Highlights need to recognize atypical presentation, understanding of multi-morbidity, shared decision making, and multidisciplinary approaches
Australia and New Zealand Society for Geriatric Medicine (2015)	Australia and New Zealand	Policy **Level 7** Policy statement, endorsed by expert committee, no reference to design process	N/A	N/A	• Position statement on the management of older adults in ED covering; multi-morbidity and complexity of care, need for evidence based approaches for improvement, the need for a patient centered and older person friendly physical environment, need for screening of at risk seniors, benefits of functional assessments, management of older adults with trauma, the requirement for psychological screening for any patient who appears confused, the desirability of a multidisciplinary approach, a requirement to consider efficiency targets in light of the needs of older patients, and the need for geriatric education. • Stresses the importance of increasing collaboration between geriatrics and emergency medicine • Focused on the need for

					person centered care
Banerjee, Conroy, and O'Leary (2012)	UK	Guideline **Level 7** Guideline- no explicit reference to systematic review of literature to define best practices. Endorsed by expert committees	N/A	N/A	• Method of development is briefly mentioned on chapter 8. Appears to have involved a single, subject matter expert writing each chapter • Reference is made to a process of voting on standards- exact methodology is not defined. • Highly likely to be potentially assessed as higher quality evidence, however, the methods described do not lend themselves to confident appraisal. • The project was jointly led by representatives of the College of Emergency Medicine and the British Geriatrics Society and sponsored by another 11 signatory organizations • Covers; quality standards for older people, challenges in urgent and emergency care, service design, older people in different clinical settings, assessment and management with 24 hours, safeguarding, training and development, of staff, major incidents involving older people, information sharing, clinical governance and research and commissioning urgent and emergency care for older people
Burton, Young and Benier (2014	USA	Journal article **Level 7** Discussion of key issues by experts in the field.	N/A	N/A	• Aging populations increasingly use ED- alternations to environment and care approach are required • Older patients are at increased risk for inadequate or insufficient care in ED • A geriatric specific approach should include

					opportunities to enhance patients encounters, adaptation of the physical space, adapted approach to medical and trauma evaluation, and neurocognitive assessment
Carpenter et al (2014)	USA	Journal article **Level 7** Announcement	N/A	N/A	• Introduction to guidelines intended to improve ED geriatric care • Explains the process of development of the guidelines- 14 clinical and academic experts in geriatric emergency medicine reviewing best practice evidence and collaboratively drafting 40 recommendations. • Recommendations covering staffing, transitions of care, education, quality improvement, equipment and supplies, and policies, procedures and protocols.
Clevenger, Chu & Zang (2012)	USA	Journal article **Level 5** Literature review of descriptive and qualitative studies	N/A	7 articles published between 1995-2009	• All literature found provided 'level 7' evidence- narrative opinion or opinions from authorities" • The articles recommended best practices for; assessment of cognitive impairment, dementia communication strategies, avoidance of adverse events, alterations to the physical environment, and education of ED staff. • There is no empirical evidence to support the conclusion these are best practice for the ED setting as most evidence is taken from residential or other acute care settings. • More research is required.
Conroy et al (2016)	Inter-national-EU	Journal Article	Members of the EU special interest group on	Self selected volunteers	• Describes the process of developing the European geriatric emergency medicine curriculum • Fist step, nominal group

		Level 6 Single descriptive study on methods used to define geriatric emergency medicine curriculum	geriatric emergency medicine.		technique used to generate domains and items based on published literature • Second step, domains and items broadened and validated using a Delphi consensus • 96 individual learning outcomes identified and categorized into; pre-hospital care, assessment, and management of older people. • Curriculum was then formally submitted to European societies for geriatric medicine and emergency medicine for approval.
Dent et al (2016)	Australia	Journal feature **Level 7** Letter to the editor	NA	NA	• More than half of older patients in ED are frail • Frailty signifies an increased vulnerability to external stressors and poor outcomes • At present, ED's are not equipped to provide the care required by frail patients • Rapid recognition and response systems are required for frail patients in ED to reduce harm, maintain dignity, and optimize outcomes
Devriendt et al (2017)	Belgium	Journal feature **Level 6** Single descriptive study	Belgian hospitals- in particular ED's and geriatric services	Initial requests sent to 100 hospitals, 49 responses received from geriatric services, 12 from ED's	• 53% of sites report there is some agreement- typical informal- between ED and geriatric services in their hospital • geriatricians are available to answer questions during the day in 96% of sites • 96% of hospitals have an onsite inpatient geriatric consultation team • 59% report patients are screened at admission to 'at risk' status • 25% of hospitals had organised geriatric training for ED staff in the previous 12 months. • 69% feel the infrastructure of ED is insufficient to offer high quality care to older patients

ED Manage-ment (2018) *	USA	Journal Article **Level 7** Announcement	N/A	N/A	• Introduces geriatric ED guidelines and discusses key points from the literature • Notes that data on outcomes and cost effectiveness is currently lacking and that future plans include primary research to gather these data •
Ellis et al (2018)	Internationa l	Journal Article **Level 7** Position statement by experts. No reference to development method or systematic review of literature	NA	NA	• Statement on minimum standards of care for older people in emergency departments • Covers,; approach to care, personnel, environment, decision making, processes, support, desired outcomes and results, and effective systems.
Hogan et al (2014)	USA	Journal Article **Level 6** Single descriptive study, on characteristics of Geriatric ED's in the US	Hospitals with self reported geriatric ED's	36 hospitals identified as 'having geriatric ED's. 24 confirmed current presence of geriatric ED	• Research aimed to determine the number, distribution and characteristics of geriatric ED's in the US • Snowball sampling to identify ED's that have 'geriatric ED programs • Survey sent to these hospitals to confirm existence of ED and characteristics • Self reported characteristics include; 70% attached to main ED, 66% have between 1-10 geriatric beds, changes to physical environment (96%) including beds (96), lighting (90%), flooring (83%), visual aids (73%) and sound level (70%). 77% have staff that overlap with the general ED, 80% require geriatric staff didactics. 67% do discharge planning in ED, and 90% do follow up post discharge via phone call.
Hogan et al (2010)	USA	Journal Article	*Phase* I emergency physicians and education experts. *Phase* II	Phase I, n= 363 participant phase II, expert panel of n=24.	• Discusses the rationale for, and development of the Geriatric Competencies for EM Residents. • Utilized and inductive, qualitative, multiphase

		Level 6 Single descriptive study, on methods used to define geriatric emergency medicine curriculum in US	experts in geriatric emergency medicine		method to determine the minimum geriatric competencies using Delphi type method • Phase I responses n363, resulting in 12 domains and over 300 competencies • Phase 2 expert panel (n=24) clustered the Phase I responses, resulting in eight domains and 72 competencies • Phase III, expert panel reduced the competencies to 26 • Phase IV, analysis of face validity and reliability yielded a 100% consensus for eight domains and 26 competencies. • The result of this research is a consensus document that can form the basis for EM residency curricula and assessment to meet the demands of an aging population
Hwang et al (2013)	USA	Journal Article **Level 7** Expert opinion on key issues	N/A	N/A	• Presents need for models of geriatric emergency care • Subjects include need to transform emergency medicine, the special care requirements for older adults, pragmatic geriatric screening and planning, redesign of service settings, ED based enhancements, and the challenge ahead. • Authors are experts in field, including researchers and physicians- however, this is simply a presentation of secondary data, no primary data included.
Joanna Briggs Institute (2012)	Australia	Journal article **Level 5** Best practice clinical guideline based on review of descriptive and qualitative studi	NA	NA	• Highlights elements of best practice nursing care for older people in ED • Reports on results from 16 papers, only one study was prospective, randomised, and single blind. Another was a quasi-experimental design research study, the remaining 14 are expert opinion presented textually with variable

					methodological quality • Review identified 39 findings of 'best practice' though note the evidence for these is not empirical. • All of the evidence presented is assessed as 'level B' using the Joanna Briggs grades of effectiveness- suggesting there is moderate support which warrants consideration.
Kennelly (2012)	Ireland	Journal Article **Level 6** Single descriptive study	Emergency Physicians, surgical and medical registrars involved in care of older people in ED	76 respondents (of 97 potentially eligible)	• 14 item self administered survey on knowledge, skills and attitudes of doctors towards cognitive impairment • Questionnaire developed using Delphi style approach, including three senior geriatricians and a senior ED physician. • 29% of respondents felt they lacked relevant expertise to perform cognitive screening • 78% felt cognitive screening was important in the ED. However, limiting factors that preclude this taking place include lack of screening tool, lack of privacy, excessive noise, and time constraints. • The staff did not feel the ED environment was conducive to cognitive screening
Martin-Khan et al (2013)	Australia	Journal Article **Level 7** Study protocol	N/A	N/A	• Describes intended method for developing quality indicators for care of older people in emergency departments including structural, process, and outcome indicators based on systematic review of literature and consultation with expert panel
McClelland &Sorrell (2015)	United States	Journal Article	NA	NA	• States that older adults need specialised care to meet their complex physical and psychological needs in ED • Suggests the challenge of increasing geriatric presentations are posing an increasing challenge to the US health system • Notes multiple challenges

		Level 7 Expert opinion and description of key challenges in emergency medicine			including; atypical presentation of disease, higher acuity, multi-morbidity, polypharmacy, functional and cognitive impairments, and communication problems. • Notes challenges that staff report with lack of time and knowledge for ED staff to provide best practice care. • Points to emerging geriatric ED guidelines as potential solution. • No evidence of systematic literature searching or standardised assessment and extraction.
Melady and Perry (2018)	Canada	Journal Article **Level 7** Expert opinion on best practices	N/A	N/A	• Suggests best practices for older adults in ED including; • Use of geriatric principles to address complexity • Educate ED staff about unique aspects of geriatric emergency care • Adopt a geriatric specific approach to rapid assessment and risk stratification, • Maintain awareness of atypical presentation of disease • Establish systems of medication management • Recognize variability of 'normal' in investigation • Establish systems to check chronic and acute cognitive impairment • Assess acute presentation in the context of the patients psychosocial needs and caregiving environment • Use palliative care principles in each assessment • Develop interdisciplinary team for acute assessment and transition planning
Miller (2012)	USA	Journal feature **Level 7** Editorial	N/A	N/A	Announces Geriatric ED guidelines
Nursing Older People (2011)*	UK	Journal Feature **Level 7** Announcement	N/A	N/A	Announces proposed geriatric standards for the UK

Parke &McCusker (2008)	Canada	Guidelines **Level 7** Guideline developed by expert panel consensus.	N/A	N/A	• The consensus development process used an international expert interdisciplinary panel, convened at an international conference • Consensus established by round table discussion and think-tank session • Followed by a nominal group method with constant comparative analysis and coding techniques to identify policy recommendations. • Reviewed and validated by external review by four independent experts. • Assigned as level seven evidence as there is no reference to systematic literature review in development. • A total of seven categories of policy • recommendations were developed: education, integration and coordination of care, resources, ED physical environment, evidence-based practice, research and evaluation, and advocacy
Parke & Hunter (2017)	Canada	Journal Article **Level 6** Single descriptive study reporting a proposed framework for dementia friendly emergency departments	N/A	N/A	• Describes the dimensions of an elder friendly hospital • Proposes indicators of success for a dementia friendly ED including measures of; clinical care systems and processes, social climate, policies and procedures, and physical environment • Reference is made to previous exploratory research, which resulted in the development of these indicators.
Perry, Tejada, Melady (2018)	USA	Journal Article	N/A	N/A	• Presents key issues in geriatric emergency medicine according to three clinical and research experts

		Level 7 Expert opinion			Key issues discussed with reference to literature include; benefits of geriatric emergency departments, cogitative impairments, atypical presentation, functional assessment, geriatric medication reconciliation, ED palliative care
Rawson et al (2017)	Australia	Journal Article **Level 6** Single descriptive study	Emergency nurses in Melbourne	N=101	• Aim of the research was to assess emergency nurses knowledge and self reported practice when caring for older patients in ED • Method was cross sectional, self administered, self reported survey of emergency nurses • On the 25 item - 'knowledge of older persons' questionnaire. mean score was 12.7 (SD 2.66) • On the 15 item "gerontic health related questions' mean score was 9.04 (SD 1.80) • nurses rated themselves as good or very good at; assessing pain (80%), delirium (94.9%), identifying (87.8%) and identifying dementia (82.8%). • Areas with poor ratings were; identifying depression (46.5%), assessing polypharmacy (46.5%) and assessing nutrition (37.8%) • Conclusion, there is a variation in knowledge and self rated practice related to care of older patients.
Ryan et al (2017)	Canada	Journal Article	Phase I: GEM nurses in Ontario/ Phase II: 96 GEM nurse Phase III: stakeholder	Phase I: n=54 Phase II= N=96 Phase III: N=47	• Provides overview of geriatric emergency management nursing practices in Ontario, Canada • Phase 1: Custom designed survey gathering characteristics of GEM nursing practice

		Level 6 Single descriptive study	s including service managers and service users		in ED • Phase II: Practice process mapping at GEM nursing network meeting • Phase III: Anonymous satisfaction evaluations distributed via regional geriatric programs • Key features of GEM nursing includes; comprehensive geriatric assessment, cognitive assessment, functional assessment, risk screening, and post discharge follow up
Saliba (2018)*	USA	Journal Feature **Level 7** Announcement	N/A	N/A	• experts from American Geriatrics Society (AGS), American College of Emergency Physicians (ACEP), and others have partnered to launch the Geriatric Emergency Department Collaborative (GEDC) for addressing present needs and future realities in U.S. emergency department (
Salvi et al (2007)	Italy	Journal Article **Level 7** Expert opinion on key challenges in emergency care	N/A	N/A	• Article analyses the epidemiological load and potential problems with elder ED patients. • critical review of organisational models, clinical approaches and methodologies in order to reduce ED physicians' difficulties and to improve quality of care and outcomes for elder patients. • Triage, clinical assessment, and discharge are identified as critical moments during an emergency care process • No explicit reference is made to search strategy or systematic approach to appraising literature is apparent.
Sanders (1999)	USA	Journal Feature **Level 7** Transcript of conference address	N/A	N/A	• Reports, in brief, on findings from SAEM taskforce on care of the older person in ED. • Concludes that emergency medicine must adopt an alternative care model recognizing the special needs of older patients.

Schnitker et al (2013)	Australia	Journal Article **Level 3** Systematic literature review of quasi-experimental studies	43 studies included	N/A	• Systematic literature review of 43 studies on evidence to guide best practice management of older patients in ED • Evidence included; interventions to improve recognition of cognitive impairment (n=9) clinical approaches to reduce falls (n=1) and reduction of delirium (n=4). Additionally, there were interventions to reduce prescription of deliriogenic drugs (n=1), reduce behavioural symptoms of dementia (n=7) and improve nutritional intake (n=1) in adults with cognitive impairment • Review of the impact of these interventions demonstrates limited evidence of improvement in quality of care for older people in ED • Furthermore, the majority of these interventions are not tested for ED. • Conclusion, additional research is required.
Shanley et al (2009)	Australia	Journal article **Level 6** Single descriptive study	3 hospitals in Sydney Australia	Total of 2,493 consultat-ions by aged care emerg-ency team (ASET)	• ASET team consists of a fulltime clinical nurse consultant, and other part time staff including at nurse, geriatric register, physiotherapist and/or occupational therapist • The nurse consultants main roles included; CGA, case findings & referral to inpatient services, fast track assessment & decision making, referrals to community services, educating ED staff, & advocacy. • Program focuses on adults with complex needs • No funding was made available for assessment of the program- no outcomes are tracked, • Despite the lack of evidence, 34 other hospitals have adopted the model in Australia.
Wolfe (2006)	Canada	Journal article **Level 6** descriptive study	N/A	N/A	Conference proceedings by GEM nurse describing the "GEM nurse model"

Appendix four: Survey development sources

This document lays out the source material for each domain, and where appropriate individual items, for the survey used in Phase One of this research. Each of the non-demographic items was identified in published academic literature and inclusion in the survey was determined by independent identification by the expert panel

Domain	Source or rationale for inclusions
Demographic and biographic details	**Rationale**: The demographic and biographic details section was modelled on the corresponding section of the Alzheimer's Society "Quality of dementia care in hospitals on a general ward" survey which was administered nationally in 2009.
Details of the admission	**Rationale**: The admission details section was modelled in part on the Alzheimer's Society "Quality of dementia care in hospitals on a general ward" survey which was administered nationally in 2009. Additionally, the expert panel suggested some items presented in this domain (most notably reason for attendance, and means of arrival) could have an impact on experience of care. Additionally, disparities in care based on time of presentation (daytime or overnight) have been reported in literature **Sources** Achterberg, W. P., Pieper, M. J. C., Van Dalen-Kok, A. H., De Waal, M. W., Husebo, B. S., Lautenbacher, S., … Corbett, A. (2013). Pain management in patients with dementia. *Clinical Interventions in Aging, Annual*, *8*(12), 1471. Retrieved from http://utah-primoprod.hosted.exlibrisgroup.com/primo_library/libweb/action/dlDisplay.do?vid=UTAH&institution=01UTAH&docId=TN_gale_hrca374812586 Ackroyd-Stolarz, S., Guernsey, J. R., MacKinnon, N. J., & Kovacs, G. (2011). The association between a prolonged stay in the emergency department and adverse events in older patients admitted to hospital: a retrospective cohort study. *BMJ Quality & Safety*, *20*(7), 564–569. http://doi.org/10.1136/bmjqs.2009.034926 Ackroyd-Stolarz, S., Read Guernsey, J., Mackinnon, N. J., & Kovacs, G. (2011). The association between a prolonged stay in the emergency department and adverse events in older patients admitted to hospital: a retrospective cohort study. *BMJ Quality & Safety*, *20*(7), 564–569. http://doi.org/10.1136/bmjqs.2009.034926 Afzal, N., Buhagiar, K., Flood, J., & Cosgrave, M. (2010). Quality of end-of-life care for dementia patients during acute hospital admission: A retrospective study in Ireland. *General Hospital Psychiatry*, *32*(2), 141–146. http://doi.org/10.1016/j.genhosppsych.2009.10.003 AgeUK. (2015). *Later Life in the United Kingdom*. Retrieved from http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/Later_Life_UK_factsheet.pdf?dtrk=true Ahmed, S., Leurent, B., & Sampson, E. L. (2014). Risk factors for

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Waiting and	**Rationale**: Previous qualitative research has found that the time

Assessment	spent in triage and waiting for assessment can have a negative impact on emotional state of a person with dementia. This has been found to be particularly true if the waiting area is over stimulating. This domain aimed to determine if there was a relationship between overall satisfaction, anxiety, and perception of dementia friendliness and the experiences of patients and carers in the waiting and assessment period. On advice of the expert panel this domain also included questions about the involvement of the patient during initial assessment, and the experience of communication during triage as they felt it would be logical to present these items in the admission section (presentation chronologically) rather than referring back to the experience of communication during triage and assessment in the communication section (presentation thematically) **Sources**: • Andrews, J. and Christie, J., 2009. Emergency care for people with dementia: Emergency Nurse, 17(5), pp.12-15. • Borbasi, S., Jones, J., Lockwood, C. and Emden, C., 2006. Health professionals' perspectives of providing care to people with dementia in the acute setting: Toward better practice. Geriatric Nursing, 27(5), pp.300-308. • Brooker, D., Leung, D., Bowley, K., Etches, C., Bray, J., Smith, P., Willoughby, J., Hampson, G. and Upton, D., 2013. The Dementia Care Bundle. Health Foundation. • Bridges, J., Flatley, M. and Meyer, J., 2010. Older people's and relatives' experiences in acute care settings: Systematic review and synthesis of qualitative studies. *International journal of nursing studies*, *47*(1), pp.89-107. • Coleman, E.A., Smith, J.D., Frank, J.C., Min, S.J., Parry, C. and Kramer, A.M., 2004. Preparing patients and caregivers to participate in care delivered across settings: the Care Transitions Intervention. Journal of the American Geriatrics Society, 52(11), pp.1817-1825 • Cunningham, C. and McWilliam, K., 2006. Caring for people with dementia in A&E: Colm Cunningham and Katie McWilliam describe some simple steps to improve care for people with dementia in A&E. Emergency Nurse, 14(6), pp.12-17 • Han, J.H., Bryce, S.N., Ely, E.W., Kripalani, S., Morandi, A., Shintani, A., Jackson, J.C., Storrow, A.B., Dittus, R.S. and Schnelle, J., 2011. The effect of cognitive impairment on the accuracy of the presenting complaint and discharge instruction comprehension in older emergency department patients. *Annals of emergency medicine*, *57*(6), pp.662-671. • Hasselkus, B. R., 1994. Three-track care: Older patient, family member, and physician in the medical visit. Journal of Aging Studies, 8(3), 291-307. • Jurgens, F.J., Clissett, P., Gladman, J.R. and Harwood, R.H., 2012. Why are family carers of people with dementia dissatisfied with general hospital care? A qualitative study.

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Treatment area	**Rationale**: Literature suggests that the environment can have a significant impact on the emotional state and overall wellbeing of a person with dementia. This section aimed to explore the potential impact of various elements of the physical and social environment of the ED. Similar to the section on waiting and assessment this section also included two questions relating to experience of care and interaction as they related specifically to this point of the admission process. The expert panel again advised for ease of completion these should be presented chronologically rather than thematically to aid with ease of completion. **Sources** • Andrews, J. and Christie, J., 2009. Emergency care for people with dementia: Emergency Nurse, 17(5), pp.12-15. • Brooker, D., Leung, D., Bowley, K., Etches, C., Bray, J., Smith, P., Willoughby, J., Hampson, G. and Upton, D., 2013. The Dementia Care Bundle. Health Foundation. • Bridges, J., Flatley, M. and Meyer, J., 2010. Older people's and relatives' experiences in acute care settings: Systematic review and synthesis of qualitative studies. *International journal of nursing studies*, *47*(1), pp.89-107. • Coleman, E.A., Smith, J.D., Frank, J.C., Min, S.J., Parry, C. and Kramer, A.M., 2004. Preparing patients and caregivers to participate in care delivered across settings: the Care Transitions Intervention. Journal of the American Geriatrics Society, 52(11), pp.1817-1825 • Cunningham, C. and McWilliam, K., 2006. Caring for people with dementia in A&E: Emergency Nurse, 14(6), pp.12-17 • Jurgens, F.J., Clissett, P., Gladman, J.R. and Harwood, R.H., 2012. Why are family carers of people with dementia dissatisfied with general hospital care? A qualitative study. BMC geriatrics, 12(1), p.57. • Miller, J., Campbell, J., Moore, K. and Schofield, A., 2004. Elder care supportive interventions protocol: Reducing discomfort in confused, hospitalized older adults. Journal of gerontological nursing, 30(8), pp.10-18. • Pytel, C., Fielden, N. M., Meyer, K. H., & Albert, N., 2009.

	Nurse-patient/visitor communication in the emergency department. Journal of emergency nursing, 35(5), 406-411. • Ridley, S.R., 2012. " Sidelined": Family Caregiver's Experience of the Emergency Department: Insights from Family Caregivers of People with Alzheimer's Disease. • Tolson, D., Smith, M. and Knight, P., 1999. An investigation of the components of best nursing practice in the care of acutely ill hospitalized older patients with coincidental dementia: a multi-method design. Journal of advanced nursing, 30(5), pp.1127-1136. • Walker, E. and Jane Dewar, B., 2001. How do we facilitate carers' involvement in decision making?. Journal of Advanced Nursing, 34(3), pp.329-337.
Staff	**Rationale**: It is widely recognised that the skills and mannerisms of the staff involved in care has a profound impact on a patient's experience. Evidence in the literature suggests that the relationship between staff and patient/carer dyads is a key to satisfaction and experience of care. The items in this domain were intended to assess the impact of interactions with staff on the overall experience of care in ED. These items are presented thematically rather than chronologically on the advise of the expert panel as they felt it would assist with recall to have them grouped this way. **Sources**: • Alzheimer's Society, 2009. Counting the Cost: Caring for people with dementia on hospital wards. Available 25/01/16 on https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=787 • Bridges, J., Flatley, M. and Meyer, J., 2010. Older people's and relatives' experiences in acute care settings: Systematic review and synthesis of qualitative studies. *International journal of nursing studies*, *47*(1), pp.89-107. • Clissett, P., Porock, D., Harwood, R. H., & Gladman, J. R., 2013. Experiences of family carers of older people with mental health problems in the acute general hospital: a qualitative study. Journal of advanced nursing, 69(12), 2707-2716. • Cowdell, F., 2010. Care of older people with dementia in an acute hospital setting. Nursing Standard, 24(23), pp.42-48. • Douglas-Dunbar, M. and Gardiner, P., 2007. Support for carers of people with dementia during hospital admission. Nursing Older People, 19(8), pp.27-30. • Hasselkus, B. R., 1994. Three-track care: Older patient, family member, and physician in the medical visit. Journal of Aging Studies, 8(3), 291-307. • Nydén, K., Petersson, M., & Nyström, M., 2003. Unsatisfied basic needs of older patients in emergency care environments–obstacles to an active role in decision making. Journal of clinical nursing, 12(2), 268-274. • Pytel, C., Fielden, N. M., Meyer, K. H., & Albert, N., 2009.

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Communication	**Rationale**: Communication is a core activity in relationship building- and integral to patient safety. Similarly to staffing, evidence suggests that communication is a key to satisfaction and improving experience of care. The items in this domain aimed to explore which facets of communication are associated with experience of, and satisfaction with, care. These items are presented thematically rather than chronologically on the advise of the expert panel as they felt it would assist with recall to have them grouped this way. • Alzheimer's Society., 2009. Counting the Cost: Caring for people with dementia on hospital wards. Available 25/01/16 on https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=787 • Andrews, J. and Christie, J., 2009. Emergency care for people with dementia. Emergency Nurse, 17(5), pp.12-15. • Borbasi, S., Jones, J., Lockwood, C. and Emden, C., 2006. Health professionals' perspectives of providing care to people with dementia in the acute setting: Toward better practice. Geriatric Nursing, 27(5), pp.300-308. • Bridges, J., Flatley, M. and Meyer, J., 2010. Older people's and relatives' experiences in acute care settings: Systematic review and synthesis of qualitative studies. *International journal of nursing studies*, *47*(1), pp.89-107. • Cowdell, F., 2010. Care of older people with dementia in an acute hospital setting. Nursing Standard, 24(23), pp.42-48. • Dekker,S., 2005. Patient Safety: A Human Factors Approach. Boca Raton,FL. CRC Press

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Severity and Satisfaction	**Rationale**: One of the goals of the survey was to understand the relationship between different variables of care and overall satisfaction to determine what elements of care- identified from other settings or other patient groups- are relevant for and important to people with dementia and their carers. Therefore, satisfaction was an important metric to capture. For ease of

	analysis, a Likert type scale was used similar to the rest of the survey. The three level–mild, moderate, severe- scale that is used to describe dementia symptoms is not linked to any medical taxonomies or diagnostic criteria. Whilst using a clinical scale may have been more academically rigorous, the expert panel felt strongly that ensuring the survey was 'accessible' needed to take precedent. While there is arguably a reasonable understanding of the difference between moderate and severe manifestations of dementia, the differentiation between mild and moderate is more ambiguous. The expert panel felt respondents may feel uncomfortable sharing the severity of the dementia symptoms, hence this near the end of the survey to allow the respondent time to become comfortable with the format and confident about what other data had been collected. The panel also felt allowing respondents to self define their severity, rather than using potentially complex biomedical taxonomy would maximize likelihood of completion.

Appendix five: Process of survey development

Action	Date	Activities
Initial panel meeting	April 19th, 2016	• Reviewed the survey aims, inclusion and exclusion criteria, and sampling strategies • Discussed how the key issues identified in the literature translate the local context. • Key issues raised in the literature organised into themes and then displayed as mind maps. • Expert panel reviewed mind maps and assessed the extent to which the mind maps adequately covered the real world issues that PWD and their carers face during hospital admission.
Feedback round 1	WC April 25th, 2016	• Initial draft of the survey developed • Initial draft circulated to the expert panel, who reviewed the content, language, accessibility, and formatting of the preliminary design • This iteration of feedback was done privately- either through e-mail or private phone call based on the preference of the individual panel member
Second panel meeting	May 12th, 2016	• Prior to meeting an updated draft was circulated • Panel members discussed each item of the survey line by line • Final design, content and layout of the survey agreed in principle subject to recirculation of final draft for validation and sign off
Sign off	May 23rd, 2016	• Final version of survey circulated for sign off of panel.

Appendix six: Survey- Person with Dementia. National.

Improving the Transition between Home and Hospital for people with memory problems

Lead investigator: Courtney Shaw

Contact e-mail:
C.J.Shaw@Bradford.ac.uk
Contact Number: 07399 839 904

If you prefer an audio-visual information guide, there is an information video which covers the same content available at: https://youtu.be/1_jkcUXeGtk

You are invited to take part in a study on communication between people with memory problems / dementia, their families, and healthcare staff during a hospital admission.

Whether or not you participate is entirely your choice.

If you do not want to participate you do not need to do anything.

This participant information sheet will help you decide if you would like to take part. It explains

- why we are doing the study
- what you will be asked to do
- what the benefits or risks may be,
- what will happen when the study is done

Please feel free to talk to other people about the study including family, friends or a trusted healthcare professional if you would like to before deciding about taking part.

What is the Purpose of this research: The purpose of this study is to better understand the experience of individuals with dementia or memory problems and family carers when they visit A&E departments or are admitted to hospital. Previous research has shown us that individuals with dementia or memory problems and their carers can find this experience stressful and challenging. Our hope is that by improving our understanding of the challenges you encounter, we will be able to improve the process to make it better for those who are admitted to hospital in future.

Who can take part: If you are person living with dementia or other memory problems and you have visited an A&E department or been admitted to hospital via A&E in England in the last two years we are interested in hearing about your experience. We are also interested in

your experience if you are the carer or supporter of someone with dementia or memory problems who has visited an A&E department or been admitted to hospital via A&E in England the last two years.
What will my participation involve? This survey will ask you about your experience of attending A&E and being admitted to hospital. There are a mix of questions, some of which will ask you to rate certain elements of the experience on a scale of 1-5 and others which give you the option of writing a short free text response. The survey should not take more than 30 minutes to complete. **If you choose to take part in this study, your completion and submission of the survey will be taken as a sign of your consent participating in this research**.

What are the possible risks? There are no physical risks in participating in this survey. However, we realize that reflecting on an experience of hospital care can be upsetting for some people. While we have tried our best to ensure the content is appropriate, some people may feel upset when they complete the survey. If you find that responding to the survey is upsetting for you, please feel free to leave the survey incomplete and end your participation. If after completing this survey, you feel you need to speak to someone about the care that was received in hospital, please contact the PALS department at the Hospital you attended, or contact your local Alzheimer's Society for support- contact details for these organisations are provided on the last page of the survey.

What happens after the study? The data collected in this study will form part of a doctoral project and will be published as a chapter in a thesis. The data which is collected in this phase of research will be used to develop interview plans which explore in more detail the issues which you raise in this survey. The data collected from this survey will be stored securely in line with UK data protection laws. If you are interested in receiving a copy of the results please contact Courtney Shaw and she will ensure you receive a summary of the results.
Thank you for taking the time to read this information sheet. If you would like to participate in this research, please indicate this by ticking the boxes on the following page, and return your completed survey to the drop box at the location you collected it from or mailing it to:
Courtney Shaw, C/O Faculty of Health Studies: University of Bradford, Richmond road, Bradford, BD7 1DP
Kind regards, Courtney Shaw

Meet the researcher: http://www.bradford.ac.uk/research/faculties/health-studies/research-students/current-students/courtney-shaw/

Consent

*Please fill in this page and **return it along with your completed survey.***

I have read and understood the information sheet above ☐

I agree to take part in this research ☐

Please tell us about yourself

1) When you attended A&E what best describes your situation?

- ○ I attended alone
- ○ I attended with a carer or supporter with me

2) Please tell us your age at the time of the admission/visit to A&E

- ○ Younger than 64
- ○ 65-74
- ○ 75-85
- ○ 85+

3) **How long ago was the admission to A&E?** *If you have experienced multiple visits/ admissions in the previous 2 years, please think about the most recent.*

- ○ than 6 months
- ○ 6 months to 1 year ago
- ○ 1-2 years ago

4) Which Hospital did you visit?

_____

About the attendance at hospital

These questions are about some of the details of your most recent admission to hospital or visit to A&E.

We understand sometimes it can be difficult to remember details or that multiple answers may be appropriate. Please give the answer you believe is most appropriate

1. **What was the main reason for attending the hospital**

   - ○ Minor accident- *sprains, cuts needing stiches, ect*
   - ○ Major accident- *broken bones, multiple injuries, blood loss, head injury ect*
   - ○ Acute illness- *existing medical condition got worse or new condition requiring urgent attention*
   - ○ Life threating injury or illness- *stroke, heart attack, multiple injuries, serious blood loss*
   - ○ Mental health- *such as significant changes in behaviour, memory, or increases in confusion*

2. **Who made the decision to attend A&E?**

   - ○ The person with Dementia
   - ○ The supporter(s) of the person with dementia
   - ○ Other family members
   - ○ A healthcare professional in the community *(i.e. a GP, A community nurse, a care provider)*
   - ○ Advised by NHS telephone helpline
   - ○ Ambulance staff/ paramedics

3. **How did you arrive at A&E?**

   - ○ Came on my own/ our own
   - ○ Brought by paramedics: **non-**emergency transfer *meaning no lights or sirens*
   - ○ Brought by Paramedics: **emergency** transfer *meaning with lights and sirens*
   - ○ Other *(please explain)*_____

4. **Approximately what time was it when you first arrived at the hospital?**

- ○ Day time *(approx 8am-5pm)*
- ○ Evening *(approx 5pm-10pm)*
- ○ Night *(approx 10pm-8am)*

5. **What happened after your visit to A&E**
   - ○ I was treated at the Minor Injuries Unit or seen by a GP at the hospital and sent home
   - ○ I was treated in A&E and sent home
   - ○ I was treated/assessed in A&E and admitted to the hospital for further treatment

Waiting and Assessment

*These questions are about the time you spent in A&E **before** you were diagnosed or treated. This may have been in waiting area with other people, in a curtained off section, or possibly in a treatment bay.*

*We understand that sometimes it can be difficult to remember details or that multiple answers may be appropriate. Please give the answer you believe is **most** appropriate.*

1. **How long were you waiting to see a doctor or nurse for the first time?**
   - ○ Less than 30 minutes
   - ○ 30minutes- 1 hour
   - ○ 1-2 hours
   - ○ 2-3 hours
   - ○ 3-4 hours
   - ○ 4+ hours
2. **There was a quieter space available for me to use in the waiting area**

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

3. **The staff member who assessed me took time to ask about any recent changes in behaviour and / or memory**

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

4. **I was encouraged and supported to share relevant medical history**

① Strongly Agree ② Agree ③ Neither ④ Disagree ⑤ Strongly Disagree

5. **I became more anxious/confused while I waited to be seen**

① Strongly Agree ② Agree ③ Neither ④ Disagree ⑤ Strongly Disagree

Treatment area

These questions are about the time you spent in A&E ***receiving treatment****. This is after you have been assessed, but before you have been admitted to a ward or sent home. During this time you may have been in a curtained off area, a treatment bay, or you may have been taken for tests such as X-rays or had medical staff come and see you to administer treatment. We understand that sometimes it can be difficult to remember details or that multiple answers may be appropriate. Please give the answer you believe is* ***most*** *appropriate.*

1) **There was a quieter space available for me to use while waiting for treatment or waiting to be admitted to a ward.**

① Strongly Agree ② Agree ③ Neither ④ Disagree ⑤ Strongly Disagree

2) **The noise level in A&E** *(sounds from other patients, machines, conversations ect*) **made me more anxious / confused**

① Strongly Agree ② Agree ③ Neither ④ Disagree ⑤ Strongly Disagree

3) **The physical space of the A&E was safe and comfortable for someone with dementia** (*ie, facilities clearly signed, clocks visible, equipment which could cause tripping/fall hazard removed*)

① Strongly Agree ② Agree ③ Neither ④ Disagree ⑤ Strongly Disagree

4) **I was able to see signs directing me to facilities such as reception and toilets.**

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

5) **My supporter was encouraged to stay with me in A&E the whole time I was there.**

1	2	3	4	5	
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	◯ I did not have a supporter with me in A&E

6) **My supporter was encouraged to stay with me when I moved** (*ie. To be taken for x-rays, moved to different areas of A&E, taken to a ward*)

1	2	3	4	5	
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	◯ I did not have a supporter with me in A&E

7) **I became more agitated/confused the longer I spent in A&E**

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

Staff

These questions are about the staff who treated you while you were in A&E.

We understand that sometimes it can be difficult to remember details or that multiple answers may be appropriate. Please give the answer you believe is ***most*** *appropriate.* **.**

1. **I felt there was enough staff in A&E to provide good care for all the patients who were there.**

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

2. **The medical staff who were providing care for me seemed to have a basic awareness of Dementia** (*this includes Doctors, nurses, care aids etc*)

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

3. **The medical staff provided dementia friendly care for me.**

① Strongly Agree ② Agree ③ Neither ④ Disagree ⑤ Strongly Disagree

4. **The non-medical staff who interacted with me seemed to have a basic awareness of Dementia** *(this includes porters, blood technicians, x-ray technician etc)*

① Strongly Agree ② Agree ③ Neither ④ Disagree ⑤ Strongly Disagree

5. **The non-medical staff provided dementia friendly care for me**

① Strongly Agree ② Agree ③ Neither ④ Disagree ⑤ Strongly Disagree

6. **The same doctors and nurses provided care for me during my time in A&E**

① Strongly Agree ② Agree ③ Neither ④ Disagree ⑤ Strongly Disagree

7. **I was comfortable with the staff who provided personal care** *(i.e. assistance with using the toilet/commode or physical examination*)

① Strongly Agree ② Agree ③ Neither ④ Disagree ⑤ Strongly Disagree

8. **I was able to raise the attention of staff to get help when needed**.

① Strongly Agree ② Agree ③ Neither ④ Disagree ⑤ Strongly Disagree

Communication

These questions are about the communication between you, your supporter(s), and the staff who you interacted with during your time in A&E.

We understand that sometimes it can be difficult to remember details or that multiple answers may be appropriate. Please give the answer you believe is ***most*** *appropriate.*

1. **The staff who provided care to me in A&E seemed to understand that I may have problems communicating**

① Strongly Agree ② Agree ③ Neither ④ Disagree ⑤ Strongly Disagree

2. **The staff in A&E who provided care to me used language that was easy to understand**

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

3. **The staff made an effort to speak to me when they interacted**

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

4. **When I was in A&E staff preferred to talk to a supporter or relative rather than me**

1	2	3	4	5	
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	○ I did not have a supporter with me

5. **I felt respected and my contribution was valued when I communicated with the staff**

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

6. **I was encouraged to participate in my care in a way I was comfortable with**

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

7. **Information about my diagnosis and care was communicated back to me promptly**

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

Overall

1. **How satisfied were you with the overall quality of dementia care that was provided in A&E?**
   - ○ Very dissatisfied
   - ○ Dissatisfied Satisfied

- ○ Neither satisfied or dissatisfied
- ○ Satisfied
- ○ Very Satisfied

2. **If you are comfortable sharing, we would like to know how you would describe the severity of dementia symptoms the person you supported was experiencing at the time of your visit to A&E / admission to hospital**
    - ○ Mild
    - ○ Moderate
    - ○ Severe

2. **We are interested in hearing your suggestions for how dementia care could be improved in the A&E department in hospitals.**

Thank you for completing this survey; we appreciate your taking the time to share your experiences with us.

We understand that reflecting on a hospital admission can be upsetting or distressing for some people. If you feel completing this survey has raised any issued which you would like to discuss further, there are resources available to you. You can call the Alzheimer's Society National Dementia Helpline on **0300 222 1122**, or you can contact the Patient Advice and Liaison Service (PALS) at the hospital you attended. The contact details for the PALS services are listed on the next page.

Thank you again for your time

Kind regards,
Courtney Shaw
Lead researcher

Appendix seven: Survey-Carer. National

Improving the Transition Between Home and Hospital for People with Memory Problems

Lead investigator: Courtney Shaw
Contact e-mail: C.J.Shaw@Bradford.ac.uk
Contact Number: 07399 839 904

If you prefer an audio-visual information guide, there is an information video which covers the same content available at: https://youtu.be/VqWxzWPWezM

You are being invited to take part in a study on the experience of hospital admission for people living with dementia and the carers who support them. This survey focuses specifically on the communication which takes place between people with dementia, their families, and healthcare staff during a hospital admission. Whether or not you participate is entirely your choice. If you do not want to participate no action is needed, you can simply ignore this request. There are no consequences for declining and you do not have to give a reason.

This participant information sheet will help you decide if you would like to take part. It explains why we are doing the study, what your participation will involve, what the benefits or potential risks to you may be, and what will happen after the study is done. Please feel free to talk to other people about the study including family, friends or a trusted healthcare professional if you would like before deciding about taking part.

What is the purpose of this research: The purpose of this study is to better understand the experience of individuals with dementia and family carers when they visit A&E departments or are admitted to hospital. Previous research has shown us that individuals with dementia and their caregivers can find this experience stressful and challenging. Our hope is that by improving our understanding of the challenges you face, we will be able to improve the process to make it better for those who are admitted to hospital in future.

Who can take part: If you are person living with dementia and you have visited an A&E department or been admitted to hospital via A&E in

England in the last two years we are interested in hearing about your experience. We are also interested in your experience if you are the carer or supporter of someone with dementia who has visited an A&E department or been admitted to hospital via A&E in England the last two years.

What will my participation involve? This survey will ask you about your experience of attending A&E and being admitted to hospital. There are a mix of questions, some of which will ask you to rate certain elements of the experience on an agreement scale and others which give you the option of writing a short free text response. The survey should not take more than 30 minutes to complete. You will have the option to close and re-open the survey if you need a break. If you choose to take part in this study, **your completion and submission of the survey will be taken as a sign of your consent to participating in this research.**

What are the possible risks? There are no physical risks in participating in this survey. However, we realize that reflecting on an experience of hospital care can be upsetting for some people. While we have tried our best to ensure the content is appropriate, some people may feel upset when they complete the survey. If you find that responding to the survey is upsetting for you, please feel free to leave the survey incomplete and end your participation. If after completing this survey, you feel you need to speak to someone about the care that was received in hospital, please contact the PALS department at the Hospital you attended, or contact your local Alzheimer's Society for support- contact details for these organisations are provided on the last page of the survey.

What happens after the study? The data collected in this study will form part of my doctoral project and will be published as part of my thesis. The data which is collected in this phase of research will be used to develop interview plans which explore in more detail the issues which you raise in this survey. The data collected from this survey will be stored securely in line with UK data protection laws. If you are interested in receiving a copy of the results please contact Courtney Shaw and she will ensure you receive a summary of the results.

Thank you for taking the time to read this information sheet. If you would like to participate in this research, please indicate this by ticking the boxes on the following page, and returning and return your completed survey to the drop box at the location you collected it from or mailing it to:
Courtney Shaw, C/O Faculty of Health Studies: University of Bradford, Richmond road, Bradford, BD7 1DP

Kind regards,
Courtney Shaw
Bachelor of Arts, University of British Columbia
MSc International Health, University of Leeds
Meet the researcher: http://www.bradford.ac.uk/research/faculties/health-studies/research-students/current-students/courtney-shaw/

Consent

Please fill in this page and return it along with your completed survey.

I have read and understood the information sheet above ☐

I agree to take part in this research ☐

Please tell us about yourself

For each question, please select the most applicable answer.

5) I am completing this survey

- ○ Alone
- ○ Together with the person with dementia whom I support.

6) Please tell us the age of the person with dementia at the time of the admission/visit to A&E

- ○ Younger than 64
- ○ 65-74
- ○ 75-85
- ○ 85+

7) **How long ago was the admission to A&E?** *If the person you support has had experienced multiple visits/ admissions in the previous 2 years, please think about the most recent.*

- ○ than 6 months
- ○ 6 months to 1 year ago
- ○ 1-2 years ago

8) Which Hospital did you visit?

_____

About the attendance at hospital

For each question, please select the most applicable answer.

1) What was the main reason for attending the hospital

- ○ Minor accident- *sprains, cuts needing stiches, ect*
- ○ Major accident- *broken bones, multiple injuries, blood loss, head injury ect*
- ○ Acute illness- *existing medical condition got worse or new condition requiring urgent attention*
- ○ Life threating injury or illness- *stroke, heart attack, multiple injuries, serious blood loss*
- ○ Mental health- *such as significant changes in behaviour, memory, or increases in confusion*

2) Who made the decision to attend A&E?

- ○ The person with Dementia
- ○ The supporter(s) of the person with dementia
- ○ Other family members
- ○ A healthcare professional in the community *(i.e. a GP, A community nurse, a care provider)*
- ○ Advised by NHS telephone helpline
- ○ Ambulance staff/ paramedics

3) How did you arrive at A&E?

- ○ Came on my own/ our own
- ○ Brought by paramedics: **non-**emergency transfer *meaning no lights or sirens*
- ○ Brought by Paramedics: **emergency** transfer *meaning with lights and sirens*
- ○ Other *(please explain)*_____

4) Approximately what time was it when you first arrived at the hospital?

- ○ Day time *(approx 8am-5pm)*
- ○ Evening *(approx 5pm-10pm)*
- ○ Night *(approx 10pm-8am)*

5) What happened after your visit to A&E

- ○ The person I supported was treated at the Minor Injuries Unit or seen by a GP at the hospital and sent home
- ○ The person I supported was treated in A&E and sent home
- ○ The person I supported was treated/assessed in A&E and admitted to the hospital for further treatment

Waiting and Assessment

*These questions are about the time spent in A&E **before** the person you support was diagnosed or treated. This may have been in waiting area with other people, in a curtained off section, or possibly in a treatment bay.*

*We understand that sometimes it can be difficult to remember details or that multiple answers may be appropriate. Please give the answer you believe is **most** appropriate.*

1) How long was the person you supported waiting to see a doctor or nurse for the first time?

- ○ Less than 30 minutes
- ○ 30minutes- 1 hour
- ○ 1-2 hours
- ○ 2-3 hours
- ○ 3-4 hours
- ○ 4+ hours

2) There was a quieter space available for the person I supported to use in the waiting area

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

3) The staff member who assessed the person I supported took time to ask about any recent changes in behaviour and / or memory

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

4) The person I supported was encouraged and supported to share relevant medical history

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

5) The person I supported became more anxious/confused while we waited to be seen

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

Treatment area

*These questions are about the time spent in A&E **receiving treatment**. This is typically after a patient has been assessed, but before they have been admitted to a ward or sent home. During this time the person you support may have been in a curtained off area, a treatment bay, may have been taken for tests such as X-rays, or had medical staff come and administer treatment.*

*We understand that sometimes it can be difficult to remember details or that multiple answers may be appropriate. Please give the answer you believe is **most** appropriate.*

8) There was a quieter space available for the person I supported to use while waiting for treatment or waiting to be admitted to a ward.

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

9) The noise level in A&E *(sounds from other patients, machines, conversations ect*) **made the person I supported more anxious / confused**

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

10) The physical space of the A&E was safe and comfortable for someone with dementia (*ie, facilities clearly signed, clocks visible, equipment which could cause tripping/fall hazard removed*)

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

11) The person I supported was able to see signs directing them to facilities such as reception and toilets.

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

12) I was encouraged to stay with the person I supported in A&E the whole time we were there.

13) I was encouraged to stay with the person I supported when they moved (*ie. To be taken for x-rays, moved to different areas of A&E, taken to a ward*)

14) The person I supported became more agitated/confused the longer they spent in A&E

Staff

These questions are about the staff who treated the person you support while they were in A&E. We understand that sometimes it can be difficult to remember details or that multiple answers may be appropriate. Please give the answer you believe is ***most*** *appropriate.* **.**

9. I felt there was enough staff in A&E to provide good care for all the patients who were there.

10. The medical staff who were providing care for the person I supported seemed to have a basic awareness of Dementia (*Doctors, nurses, care aids etc*)

11. The medical staff provided dementia friendly care for the person I supported.

12. The non-medical staff who interacted with the person I supported seemed to have a basic awareness of Dementia *(porters, bloods, x-ray technician etc)*

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

13. The non-medical staff provided dementia friendly care for the person I supported

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

14. The same doctors and nurses provided care for the person I supported during their time in A&E

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

15. The person I supported was comfortable with the staff who provided personal care *(i.e. assistance with using the toilet/commode or physical examination*)

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

16. **I was able to raise the attention of staff to get help when needed**.

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

Communication

These questions are about the communication between you, the person you support, and the staff who you interacted with during the time in A&E. We understand that sometimes it can be difficult to remember details or that multiple answers may be appropriate. Please give the answer you believe is ***most*** *appropriate.*

8. The staff who provided care to the person I supported in A&E seemed to understand that they may have problems communicating.

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

9. The staff in A&E who provided care to for the person I supported used language that was easy to understand

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

10. The staff made an effort to speak to the person I supported when they interacted

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

11. I felt the staff preferred to talk to me rather than the person I supported while we were in A&E

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

12. I felt respected and my contribution was valued when I communicated with the staff

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

13. I was encouraged to participate in the care of the person I supported in a way I was comfortable with

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

14. I felt I was asked or expected to take on more caring responsibility than I was comfortable with

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

15. Information about the diagnosis and care of the person I supported was communicated promptly

1	2	3	4	5
Strongly Agree	Agree	Neither	Disagree	Strongly Disagree

Overall

3. How satisfied were you with the overall quality of dementia care that was provided in A&E?

- ○ Very dissatisfied
- ○ Dissatisfied Satisfied

- ○ Neither satisfied or dissatisfied
- ○ Satisfied
- ○ Very Satisfied

4. **If you are comfortable sharing, we would like to know how you would describe the severity of dementia symptoms the person you supported was experiencing at the time of your visit to A&E / admission to hospital**
    - ○ Mild
    - ○ Moderate
    - ○ Severe

3. **We are interested in hearing your suggestions for how dementia care could be improved in the A&E department in hospitals.**

Thank you for completing this survey; we appreciate your taking the time to share your experiences with us

We understand that reflecting on a hospital admission can be upsetting or distressing for some people. If you feel completing this survey has raised any issued which you would like to discuss further, there are resources available to you. You can call the Alzheimer's Society National Dementia Helpline on **0300 222 1122**, or you can contact the Patient Advice and Liaison Service (PALS) at the hospital you attended.

Thank you again for your time.
Kind regards,
Courtney Shaw
Lead researcher

Appendix eight: REC favourable opinion (Phase One)

Health Research Authority
South Central - Oxford C Research Ethics Committee
Level 3, Block B
Whitefriars Building
Lewins Mead
Bristol
BS1 2NT

Telephone: 0207 104 8049

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

19 September 2016

Miss Courtney Shaw
PhD student: University of Bradford
University of Bradford
Horton A Building, Richmond Road
Bradford
BD7 1DP

Dear Miss Shaw

Study title:	**Optimising the Transition from Home to Hospital: Enhancing Communication between Care Partners to Improve the Quality of Dementia care in Hospital**
REC reference:	**16/SC/0487**
IRAS project ID:	**194811**

The Proportionate Review Sub-committee of the South Central - Oxford C Research Ethics Committee reviewed the above application on 07 September 2016.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Maeve Ip Groot Bluemink, nrescommittee.southcentral-oxfordc@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Appendix nine: Recruitment poster

Appendix ten: Blank observations pro forma

Observations

Hospital: _____
Date: _____
Time: _____

Entry:

Waiting areas:

Triaging:

Treatment area:

Interactions:

Appendix eleven: Excerpt from observation notes

12.15- 12.57pm. Majors area. Nursing station.
25/09/17. Site Two.

- (12:14) The family members of the patient waiting for discharge asks about the availability of food. They are directed to leave the department and get food from the Costa or the canteen. (*They seem surprised by this response?*)

- (12:17) NIC at nurses desk asked to doctors about the plans for their patients- the doctors explain. The doctors leave. As they walk away the NIC complains that "*no one is communicating with us*" (*frustration. Poor communication within the teams? Something to explore in the interviews*)

- (12:18) I can hear but not see, the nurse helping the older person who has just been brought in by ambulance- now in Bay three- change into a gown. (She's talking with her and joking with her as she does so. I can hear laughing. It seems they have a good rapport)

- (12:19) The two senior nurses at the board are arranging breaks for their staff.

- (12:20) A doctor asked the NIC for the bleep for the frailty team- it's not written on the numbers guide at the nurse's station. She walks to the doctors area to get it for them (*The NIC seems un-phased by this request, but surely the doctor could get it themselves if its in their area? I wonder if the doctor assumed the NIC would already know it by heart?)*

- (12:23) The doctor comes and tells off the healthcare assistant for not getting adequate fluids into their patient as it's been written on their chart for an hour and a half that they need IV fluids. (*The HCA seems annoyed by the way the doctor has spoken to them- in the previous 30 minutes I have observed the HCA doing quite a few activities in the department, I wonder if the are feeling unfairly critiqued for not knowing what was in the notes? Is this potentially a communication failure?*)

- (12:27) Another doctor comes by and asks what I'm doing- I explain- and they respond "*it's much more challenging the more older people there are in the department."* He goes on to say he is aware of a boot camp which is being run by Imperial College in October which offers training on communicating with older people and their family in the emergency department. (It appears to me this doctor has identified communication as an issue? That would fit with the survey findings. I wonder why they are telling me this/ is it

for my benefit, or to demonstrate the staff at the unit have an existing awareness of the issue?)

- (12:26) The NIC tells off the junior doctors again for failing to clear their sharp strays (*this interaction is more abrupt than the one earlier. The department is getting busier and it seems the NIC is getting frustrated by some of the staff- especially the junior doctors*)

- also (12:26) the Matron has come out of her offie and is arranging transport for one of the older patients in the Department. She is speaking directly to the nursing home to see if they can send a car to collect them. She says there could be a long wait for transport. (*Is this usual practice? I don't recall seeing the matron doing this in other observation sessions? Something to explore in the interviews*)

- (12:35) The NIC, consultant and matron get together at the 'board' for a conversation. The matron says there are no beds in the hospital. This will make flow difficult. (*No one looks happy. There are still spaces in ED, but based on their reactions, I think they believe things are going to get harder very quickly. I wonder if this is undue anticipatory anxiety? I think this could become a very interesting session of observation. How will the staff and the managers react?)*

- (12:40) The hospital operations manager has come to the ED to speak with the matron, NIC and consultant. They are discussing how to clear the waiting room. The operations manager says at 2 o'clock they should start tagging patients who are suitable to be seen by the GP as designated for the Out of Hours clinic which starts at 5pm. (*This will mean a three hour wait for the patients in the waiting room… are they doing to tell the patients they wont be seen until 5 at minimum? If that was a person with dementia, maybe they would prefer to go home, or to an alternative location to wait*?)

- (12:48) the surgical consultants arrive in the emergency department. There's nowhere for them to review the patient's that they've been asked to come and see. There's a disagreement between the surgeon and the nurse in charge about the best way to process patients in order to get them seen expediently. (The NIC seems angry at the surgeon? He didn't speak to her with particular respect, or ask how things were going before starting to make suggestions of how to address the bed shortage)

- (12.53) The disagreement between the surgeon and the NIC continues. The surgeon proposed using the three available beds in the short stay unit to do assessments. The NIC says there is insufficient staff to safely man that area,

and she's not willing to have patients admitted when she has no nursing staff to perform intervention or observation. She asks if an extra nurse can be brought down to any from somewhere else in the hospital to look after the surgical patients who are potentially being reviewed in the short stay area. (*The disagreement seems to centre on what is the bigger safety issue? A patient not being reviewed expediently, or the risk of unsupervised patients deteriorating. The NIC appears to be getting angry with the surgeon. The surgeon keeps saying 'surely there is something you can do' and every time he says it she grits her teeth. She is incredibly polite to him, but it wouldn't surprise me if she wanted to tell him to piss off entirely*)

- (12.57) The surgeon asks an ED Doc if he can just quickly pop one of his patients into the OBS area to do some assessments. The Doc says yes, but the NIC overhears. She tells him "*this is my department, don't you dare try to go around me. I said n*o" (*She is almost shouting at him. He seems embarrassed to be caught and apologises. She stalked off after the intervention. I think the strain may be getting to her. This is worth exploring in an interview if I can grab her at some point. Possibly some ED/broader hospital or doctor/nurse power dynamic that warrants exploring?)*

Appendix twelve: Example Case study from observation notes

Black status: A case study
Observations 8am-12pm

I start my observations this morning by the main nursing station. The ED is full to capacity at 8am. The unit 'dashboard' is showing as a red across the various domains of escalation. There have been eleven "four hour" breaches since midnight. One of the wards in the hospital has been closed, the surgical assessment unit has been transferred into an acute medical unit and one of the paediatric wards is understaffed so they can only take eight patients rather than the usual 14. There are serious problems with patient flow today. No beds are expected to become available until at least 12 PM. The escalation board is showing as a red. Currently there are three patients who have had a decision to admit who can't be moved out at the ED due to the lack of beds.

ED is understaffed today as two nurses have cancelled their ED shifts in favour of working on an acute medical unit. The unit "dashboard" is indicating that staffing levels are 'Amber' which means there are insufficient nurses or doctors for the number of patients, and that the staffing shortage could effect safety.

The Nurse in Charge (NIC) tells me there are several patients with dementia in the department today- including one with a patient has dementia and his wife is attending with him who also has dementia. The in-reach team has been called and are expected to be in the department soon to help assess the multiple older patients. When they arrive (8.30am) the NIC informs them that there are two patients with dementia who are being held in the ED department because there are no medical beds available. She requests that they start their assessments with the patients in ED rather than the short stay unit. Of particular concern to her is the patient who has been in the ED for nearly 10 hours despite being assessed as "likely safe for discharge' by the doctors overnight- the doctors will not sign off on his discharge until he has been reviewed by the in-reach team.

At 9am the duty manager for the hospital comes to the hospital to review the situation. As she arrives she encounters a family member who is standing outside of the resuscitation area crying heavily. She speaks to the family member for a short time and offers a box of tissues to the crying woman before they return to the resus area. The duty manager informs the NIC that the family of the patient in resus has just been told their relative is unlikely to live- she asks the NIC to please cascade this information quietly amongst the staff so they can be empathetic and understanding. As she and NIC begin to discuss the bed management situation, another ambulance crew arrives with a new patient. The NIC directs the crew to take the patient to the resus area despite the patient's relatively stable condition as there is no other place in the department.

Though the department is operating at capacity and is short staffed, routine care is still carrying on. The NIC encourages the nurses to ensure that patients have had breakfast and have been offered tea or coffee. She reminds them that "*fed patients are mobile patients, and mobile patients go home*". During this period between 8.30-9.30am both the NIC and consultant in charge of the department come to speak to me about my research and comment that this session of observation will likely be very interesting for me as it was likely to get chaotic. The consultant notes that ED staff are '*scuppered'* by poor bed flow, and things are bound to deteriorate despite everyone's best efforts.

At 9.30 the NIC receives a call from one of the wards- the ward would like to transfer a patient from their ward back down to the ED as the patient has chest pains and the ward does not feel equipped to manage a potential cardiac arrest. The NIC refuses the transfer saying the patient has already been reviewed by the ED team and there is no space for the patient. As she hangs up the NIC comments that her resus area is almost full already- mostly with non-acute patients- and wonders aloud what they would do if a proper 'emergency' arrived with short notice.

At 9.30 a chaplain arrives to visit the family in resus whom had earlier received the upsetting news. The chaplains presence temporarily frees the nurse from resus to come check in with the NIC at the nursing station. The dementia and in-reach teams have dissipated around the department and are carrying out assessments on four separate patients in the department. The NIC has asked the matron to work at the nurses station rather than in her office to enable an 'extra set of eyes' on the floor. The duty manager has relocated her mobile office to the medics station and is observing the department while on the phone trying to arrange patient transfers to free up beds. At one point I see the matron escorting a patient to the washroom, and at another time I see the duty manager bringing a relative a cup of tea.

At 9:42am another ambulance arrives with an older patient and their relative. The NIC shakes her head at the ambulance crew as they bring the patient in and she remarks "*there is no room*". The ambulance crew respond "*well that's new*". The NIC indicates that she will take the handover and the paramedic begins explaining that the patient needs to be admitted quickly. They explains that the patient has been deteriorating at home because he didn't want to bother anyone, but now he's acutely unwell. The paramedic continues sharing his observations and the patients test results until the NIC says "*okay right I'll do what I can*".

The NIC decides that they need to move people around and use the paediatrics bed (bed 11) to make space for this new acutely unwell patient in the resuscitation area. She decides that the patient in bay five can go into bay eleven, the patient from resus bed two can go into bay five, and then the new patient can be brought into resus 2. The patient who is moved from bay five to bay eleven is an older patient who has unspecified 'confusion' and is awaiting review by the in-reach team.

At 9:50 another ambulance crew arrives. The NIC has no place to put this new patient, and direct the ambulance crew to start a queue in the hall- none of the nurses are available to take handover, so the ambulance crew stays with the patient. There are now six patients who have a decision to admit but there are no beds in hospital. From the nurse's station I can see a television screen that shows the waiting room with multiple patients who are waiting to be seen. The patient who was moved from bay five 5 (which is right beside the nurses station and highly visible) to bay eleven (the paediatric bed in a separate room) has started to cry loudly. She is pulling at her bed sheets and calling out *"please help me, please help me, please help me*". Because of the location of her bed, the nurses doing charting at the desk are unable to see or hear her. One of the doctors walks past and notices her distress- they comment to the nurses someone might need to go check on her. As he is leaving a patient asks the doctor to get a nurse for them so they can get a glass of water. The doctor says "*I've got a moment, I'll be right back*" and brings the patient a glass and small pitcher of water before returning to his desk to work on his computer.

At 10:18am the band seven matron comes to speak to the NIC about the conditions in the department- they both agree that they're now operating on the margins of safety. The matron proposes requesting an emergency nurse practitioner (ENP) from another area in the hospital. She suggest this would enable the nurse currently doing triage to provide an extra hand and supervision in the hall queue. They Matron calls to make the request, but no ENP's are available. The matron says, "*fine, then we will just have to hold an ambulance crew here and accept the (South Central) Ambulance breach penalty*".

The patient in bed 7 has been declared medically fit for discharge by the in-reach team. He is very close to becoming a 12 hour breach. The matron and NIC discuss how to manage the situation. They are both very keen to free up the bed to enable proper assessment of the patients in the hallway queue. However, because of the dementia, it is not possible to discharge the man without a family member coming to collect them- the man's brother is on his way, but will be at least another hour. They discuss whether it is possible to put him in a discharge lounge or the short stay unit, but both are rejected as they are not observable and he is a high falls risk. Eventually, they agree that he will have to stay where he is despite the 12 hour breach. This frustrates both the matron and the NIC, but as they conclude their conversation agree that "*it's a safety issue, it's a pain, but safety has to come first*". Several porters arrive with hospital beds and the Matron gets disinfecting wipes and sheets and starts preparing the beds to enable the patients in the hall queue to be taken off trolleys.

At 10.24 a nurse goes to visit the patient in bay eleven who is distressed and crying out. They spend ten minutes in the room with the patient, and leave the door wide open to enable the patient to see the rest of the department as they leave. By 10.40 the patient in Bay eleven is distressed and crying again. The nurse returns with an incontinence pad and fresh clothing and closes the door again.

At 10: 40 the NIC, consultant in charge, and the duty manager have a meeting at the board. The NIC says "*this is not safe*" and indicates that she thinks they should be diverting ambulances to [redacted].

At 10.54 another ambulance arrives with a patient who is suspected to have had a stroke. The stroke co-coordinator has been pre-alerted and is in the department waiting for the ambulance to arrive. There are no beds available, so the stroke co-coordinator begins his assessment in the hallway.

At 10:57 the NIC tells the junior doctors that the consultant has now officially escalated "*we are now unsafe*" to the hospital management. She explains they can't take patients out of the cubicles to put them back in the hall queue to enable assessment of new patients as there are insufficient nursing staff to safely care for patients in the queue. The hospital is now holding ambulances and there is still a three hour waits for any medical beds.

At 11.03 I observed the HCA assistant from short stay offering tissues and comfort to the family member who was visited by the chaplain earlier, she is crying again. There are two nurses by the nurses station discussing how challenging it is to get a community hospice bed, and how awful it must be to be dying in a busy emergency department. As they depart, the NIC reminds them to keep an eye out for the family and ask if there is anything that can be done.

By 11.15 there are six patients in the hallway queue, and a senior team leader from [redacted] Ambulance service arrives. He speaks with the NIC and they agree to release 5 of the 6 ambulance crews to prevent further ambulance hold breaches. The team leader and remaining ambulance crew are now responsible for all the patients in the hall queue.

At 11.20 a consultant moves to the waiting room to take over triaging- they indicate before heading out to the waiting area that there is a concern without senior oversight a serious illness or deterioration will be overlooked given the high stress environment.

At 11.20 the in-reach team reports that two of the patients they have seen that morning are safe to be discharged. They were able to explain the situation to their colleagues in the community and rapidly assemble additional care for the patients so they could be discharged. They have arranged transport for these two patients, and two ED bays will soon be available. The NIC expresses her gratitude and arranges for these two bays to be used as assessment bays. The consultant is now pulling patients from the waiting area to be assessed in these two bays, and returning them to the waiting room after assessment. Several of these patients have cannula's inserted while they are assessed and return to the waiting room with IV fluids being administered.

11:30 the NIC calls the duty manager again to report on the conditions in the department. She indicates that they are going to have to start calling GP surgeries and declaring they are no longer available for urgent referrals. The bed manager assures her that there is movement happening, and beds should be coming available shortly. The matron is again out of her office and on the floor assisting the staff nurses and directing patients.

By 12pm when the observations concluded, there were 5 patients still in the hallways queue. The waiting room had approximately 15 people waiting to be seen, and despite multiple efforts to re-deploy staff from other areas in the hospital, no additional staff had been sent to A&E. There were 8 patients who had a 'decision to admit' indicator by their name on the board, but no-one had moved out of the department. As I was packing up porters were starting to arrive in the department to transfer patients.

Over the course of the morning, the department escalated from uncomfortably full to dangerously overcrowded. Watching the response from the staff as these conditions changed was enlightening. As the crowding grew worse, the senior nursing staff re-positioned themselves within the department to better assist with maintaining a safe environment. When it became clear that additional resources were needed the duty manager responded quickly. When no additional resources were available, the duty manager and matron took it upon themselves to participate in hands on care and support to enable the staff nurses and NIC to continue their work.

The specialist teams that were working in the department liaised frequently with the staff nurses and NIC to ensure they were keeping each other informed. The in-reach team was able to rapidly mobilize community resources to prevent unnecessary admissions, and reduce some of the pressure on the ED.

Despite the high stress environment, the senior management maintained a calm, well-ordered department. The NIC was ensuring that her staff were supported to take their breaks as planned, and made herself available to assist with challenging patients. When the NIC was unavailable to support her staff nurses due to being occupied with managerial responsibilities, the matron made herself even more visible and available to support the staff nurses.

What was most noticeable about today was the priority that was given to safety and holistic care. While the frustration over penalties for breaches was notable amongst the senior staff, it was treated as a secondary concern to the safety of the patients. Additionally, the senior nursing staff were encouraging the staff nurses to continue providing holistic and empathetic care both to the patients and family members in the department.

Appendix thirteen: Notice of Observation in progress

Improving the Quality and Safety of Care for Patients with Dementia in the Emergency Department

Version: 1.1 **Date:** 24/05/17

Name of Researcher: Courtney Shaw

Study Number: 219697

Observation is in progress in this Department.

A researcher is watching how staff interact with older patients and their families. The observation will last for 4 hours. No names of patients, staff or visitors are being recorded. The researchers presence in the department will not affect your care.

It is part of a research study exploring ways to make accident and emergency departments safer for people living with dementia.

If you are unhappy with the observation proceeding, please speak to the researcher, or a member of staff.

Want to know more? Please contact Courtney Shaw on: C.J.Shaw@bradford.ac.uk

Appendix fourteen: Staff information sheet

Improving the quality and safety of care in emergency departments for people with dementia

Ethics committee ref:
Lead investigator: Courtney Shaw
Contact number: 07399 839 904
Contact e-mail: C.J.Shaw@Bradford.ac.uk

Introduction

You are being invited to take part in a study on the experience of caring for people living with dementia in the emergency department. This research focuses specifically on understanding the interactions that take place between people with dementia, their families, and healthcare staff during a hospital admission to find ways to improve the quality and safety of care that is provided in future.

This information sheet will help you decide if you would like to take part. It explains:

- Why we are doing the study
- What your participation would involve
- What the benefits or potential risks to you may be, and
- What will happen after the study is done.

Please feel free to talk to other people about the study including family, friends or a trusted healthcare professional if you would like before deciding about taking part.

If you would like to have a conversation with the researcher before deciding if you would like to take part, please feel free to contact Courtney Shaw on 07399 839 904 **or** C.J.Shaw@Bradford.ac.uk.

This research has been reviewed and approved by the [redacted] Research Ethics committee. The research ethics committee is a group whose task it is to make sure that research participants are protected from any distress or harm from actually taking part in a study. If you

wish to find about more about the NHS REC, [redacted]

Purpose of the research

- The purpose of this study is to better understand the experience of caring for individuals with dementia when they are admitted to hospital via the A&E department.
- We know that people with dementia are more likely to have accidents and experience avoidable harm while they are in the hospital.
- Our hope is that by improving our understanding of your experience of being in A&E we will be able to improve services to make the hospital safer and more pleasant for those who are admitted in the future.

Why have you been asked to participate?

- [redacted] Hospital have agreed to participate in this research project and you have been identified as potentially eligible because of your role in providing clinical care in the emergency department.
- We believe that your experience could be valuable in helping us identify what goes well and what does not to help improve the quality and safety of care in the emergency department for people with dementia.

What is involved in participation?

- Participation in this research project involves talking to a researcher about your experience of caring the people for dementia in the emergency department.
- During the interview you will be asked about a time when you feel you are able to provide high-quality care for someone with dementia, and conversely a time where you felt you were unable to provide high-quality care. Using those examples, you'll be guided through process of identifying some of the systemic and environmental barriers that could be addressed.
- You will also be asked about what information you need from people with dementia and their family carers to provide high-quality care.
- We can meet at the hospital, or another location that is convenient for you.

- If you decide to participate, the researcher will contact you to arrange a time to meet.

Whether or not you participate is entirely your choice. If you do not want to participate no action is needed, you can simply ignore this request. There are no consequences for declining and you do not have to give a reason.

How long will participation take?

We anticipate that sharing your experience will take around 30-45 minutes

The main priority of the researcher is to ensure you have an opportunity to fully share your experiences without creating a burden for you.

Risks

- There are no physical risks in participating in this research project. However, we realize that participating in research project such as this can be upsetting for some people.
- If during the course of the interview you do not want to answer a particular question you can request that the question be skipped or decline to answer.
- If you find yourself feeling upset or overwhelmed, you can let the researcher know and we can temporarily pause the interview to give you a break. After this break you can decide if you would like to continue your participation, request that the researcher arrange another visit to continue at a later date, or you can decide to end your participation outright.

Benefits

There are no direct benefits to you as a result of your participation. However, your input can help us improve the services we provide in hospital to make care safer and more dementia friendly.

Reimbursements

You will not be paid for your participation, but any out of pocket costs (i.e parking costs or travel tickets) that you incur as a result of your participation can be reimbursed.

Confidentiality and anonymity

- What you say to the researcher will be kept fully confidential.
- The information you share will be used to write a report, but your name and any other identifying details- such as your current position- about you will be removed to protect your anonymity.
- You can request a copy of the transcript of your interviews if you would like to review what has been written before it's included in the report
- The only time the researcher would share what you have said is if she fears for your safety, the safety of people around you, or you report an event that carries a legal obligation to report such as abuse or neglect.
- While the final reports from this project will be shared with the hospital trust your participation will have no impact on your employment.

What happens after the study?

- The data collected in this study will form part of my research project and will be published as part of my thesis.
- I will use this data to develop an intervention that aims to improve the quality and safety of care provided in A&E for people with dementia. Once this intervention is designed it will be tested in a small number of hospitals in the area.
- Before publication all materials will be fully anonymised to protect your identity.
- The data collected as part of this research will be stored securely in line with UK data protection laws.
- If you are interested in receiving a copy of the results please contact Courtney Shaw and she will ensure you receive a summary of the results or arrange a meeting or phone call to discuss the findings.

Right to Refuse or Withdraw

As noted above, Whether or not you participate is entirely your choice. If you do not want to participate no action is needed, you can simply ignore this request. There are no consequences for declining and you do not have to give a reason.

If you decide to participate and do an interview with the researcher, but later change your mind and do not want your data included in the

project, you can contact the researcher and request that your data be removed and destroyed.

Who to contact

- If you would like more information about this project, please feel free to contact the researcher Courtney Shaw on 07399 839 904 or C.J.Shaw@Bradford.ac.uk.

Thank you for taking the time to read this information sheet. If you would like to participate in this research, or you are interested in having a conversation with the researcher to decide if you would like to participate, please fill in the contact form on the next page and the researcher will be in touch with you once you/ your relative has been discharged from the hospital to arrange a time to speak.

Kind regards,
Courtney Shaw
Bachelor of Arts, University of British Columbia
MSc International Health, University of Leeds
Meet the researcher: ***http://www.bradford.ac.uk/research/faculties/health-studies/research-students/current-students/courtney-shaw/***

Appendix fifteen: Promotional flier

Would you like to participate in a research project on improving the quality and safety of care for patients with Dementia in the emergency department?

This hospital is involved in a project funded by the Alzheimer's Society to identify approaches to care that keep patients with dementia safe in A&E. Participation involves sharing your experiences in a 30 minute interview.

Please contact the researcher Courtney Shaw on C.J.Shaw@bradford.ac.uk or 07415827558 for more information

Version 1.2
19 June 2017

Appendix sixteen: Patient/carer information sheet

Improving the quality and safety of care in emergency departments for people with dementia

Ethics committee ref:
Lead investigator: Courtney Shaw
Contact number: 07399 839 904
Contact e-mail: C.J.Shaw@Bradford.ac.uk

If you prefer an audio-visual information guide, there is an information video that covers the same content available at [redacted]

Introduction

You are being invited to take part in a study on the experience of being in accident and emergency for people living with dementia and the family or friends who support them during that time. This research focuses specifically on understanding the interactions that take place between people with dementia, their families, and healthcare staff during a hospital admission to find ways to improve the quality and safety of care that is provided in future.

This participant information sheet will help you decide if you would like to take part. It explains why we are doing the study, what your participation will involve, what the benefits or potential risks to you may be, and what will happen after the study is done. Please feel free to talk to other people about the study including family, friends or a trusted healthcare professional if you would like before deciding about taking part.

Please feel free to talk to other people about the study including family, friends or a trusted healthcare professional before deciding about taking part.

If you would like to have a conversation with the researcher before deciding if you would like to take part, please feel free to contact Courtney Shaw on 07399 839 904 **or** C.J.Shaw@Bradford.ac.uk.

This research has been reviewed and approved by [redacted] Research Ethics committee. The research ethics committee is a group whose task it is to make sure that research participants are protected from any distress or harm from actually taking part in a study. If you wish to find about more about the NHS REC, [redacted]

Purpose of the research

- The purpose of this study is to better understand the experience of individuals with dementia and family carers when they are admitted to hospital via the A&E department.
- Previous research has shown us that individuals with dementia and their caregivers can find this experience stressful and challenging.
- We also know that people with dementia are more likely to have accidents and experience avoidable harm while they are in the hospital.
- Our hope is that by improving our understanding of your experience of being in A&E we will be able to improve services to make the hospital safer and more pleasant for those who are admitted in the future.

Why have you been asked to participate?

- [redacted] have agreed to participate in this research project and you have been identified as potentially eligible because you recently received care in the emergency department.
- We believe that your experience could be valuable in helping us identify what goes well and what does not to help improve the quality and safety of care in the emergency department for people with dementia.

What is involved in participation?

Participation in this research project involves talking to a researcher about your relative's recent admission to hospital. If you decide to participate, the researcher will contact you once your relative has been discharged from hospital to arrange a time to meet. We can meet at your home, or another location that is convenient for you.

The way we collect this data the will depend on your preferences.

- If you feel comfortable participating in one longer session, we can complete the interview in one visit.
- If you would feel more comfortable with a few shorter visits, we can be flexible to suit your preferences

Whether or not you participate is entirely your choice. If you do not want to participate no action is needed, you can simply ignore this request. There are no consequences for declining and you do not have to give a reason.

How long will participation take?

We anticipate that sharing your experience will take around 90 minutes. As mentioned above the way we collect this data the will depend on your preferences. **The main priority of the researcher is to ensure you have an opportunity to fully share your experiences without creating a burden for you**.

Risks

- There are no physical risks in participating in this research project. However, we realize that reflecting on an experience of hospital care can be upsetting for some people.
- If during the course of the interview you do not want to answer a particular question you can request that the question be skipped or decline to answer.
- If you find yourself feeling upset or overwhelmed, you can let the researcher know and we can temporarily pause the interview to give you a break. After this break you can decide if you would like to continue your participation, request that the researcher arrange another visit to continue at a later date, or you can decide to end your participation outright.
- You can request to have another person present if that would make you more comfortable.
- At the end of the interview you will be given contact information of the researcher and of several organizations you can contact if you find that talking about your time in hospital has been upsetting.

Benefits

There are no direct benefits to you as a result of your participation. However, your input can help us improve the services we provide in hospital to make care safer and more dementia friendly.

Reimbursements

You will not be paid for your participation, but any out of pocket costs (i.e parking costs or travel tickets) that you incur as a result of your participation can be reimbursed.

Confidentiality and anonymity

- What you say to the researcher will be kept fully confidential.
- The information you share will be used to write a report, but your name and any other identifying details about you will be removed to protect your anonymity.
- The only time the researcher would share what you have said is if she fears for your safety, the safety of people around you, or you report an event that carries a legal obligation to report such as abuse or neglect.
- In the event that happens, the researcher will explain that you have made a declaration that requires reporting and explain in detail what that means.

What happens after the study?

- The data collected in this study will form part of my research project and will be published as part of my thesis.
- I will use this data to develop an intervention that aims to improve the quality and safety of care provided in A&E for people with dementia. Once this intervention is designed it will be tested in a small number of hospitals in the area.
- Before publication all materials will be fully anonymised to protect your identity.
- The data collected as part of this research will be stored securely in line with UK data protection laws.
- If you are interested in receiving a copy of the results please contact me (Courtney Shaw) and I will ensure you receive a summary of the results or arrange a meeting or phone call to discuss the findings.

Right to Refuse or Withdraw

As noted above, whether or not you participate is entirely your choice. If you do not want to participate no action is needed, you can simply ignore this request. There are no consequences for declining and you do not have to give a reason. Your decision will have no impact on the care that you receive in the hospital now, or in the future.

If you decide to participate and do an interview with the researcher, but later change your mind and do not want your data included in the project, you can contact the researcher and request that your data be removed and destroyed.

Who to contact

- If you would like more information about this project, please feel free to speak to the research nurse who has given you this information sheet.
- You can also contact the researcher Courtney Shaw on 07399 839 904 or C.J.Shaw@Bradford.ac.uk.

Thank you for taking the time to read this information sheet. If you would like to participate in this research, or you are interested in having a conversation with the researcher to decide if you would like to participate, please fill in the contact form on the next page and the researcher will be in touch with you once you/ your relative has been discharged from the hospital to arrange a time to speak.

Kind regards,
Courtney Shaw
Bachelor of Arts, University of British Columbia
MSc International Health, University of Leeds
Meet the researcher:
http://www.bradford.ac.uk/research/faculties/health-studies/research-students/current-students/courtney-shaw/

Appendix seventeen: Blank permission to contact form

Improving the quality and safety of care in emergency departments for people with dementia- Post-Discharge follow up

Ethics committee ref: 219697
Lead investigator: Courtney Shaw
Contact number: 07415827558
Contact e-mail: C.J.Shaw@Bradford.ac.uk

If you are interested in hearing more about this research project once you have been discharged from the hospital, please fill in this form and leave it with a member of staff.

Filling in this form does not mean you have agreed to participate in this research project. It simply allows the researcher, Courtney Shaw, to contact you once you have left the hospital to share more information. You can change your mind if you decide after you have been discharged that you are not interested in hearing more about the research. Your personal data will be stored securely in compliance with UK data protection laws.

Your name(s):

_____

Your phone number:

_____

Your e-mail:

_____

Your address:

_____

Please circle one option: What is the best way to contact you about future opportunities to participate in this research?

Phone *Please incidate the time which suits you best:* ***Morning*** ***Afternoon*** ***Evening***
Email
Mail

Appendix eighteen: Certificate of consent

UNIVERSITY of BRADFORD

Certificate of Consent

Study Title: Improving the quality and safety of care in emergency Departments for people with dementia
Ethics committee ref:
Lead investigator: Courtney Shaw
Contact number: 07415827558

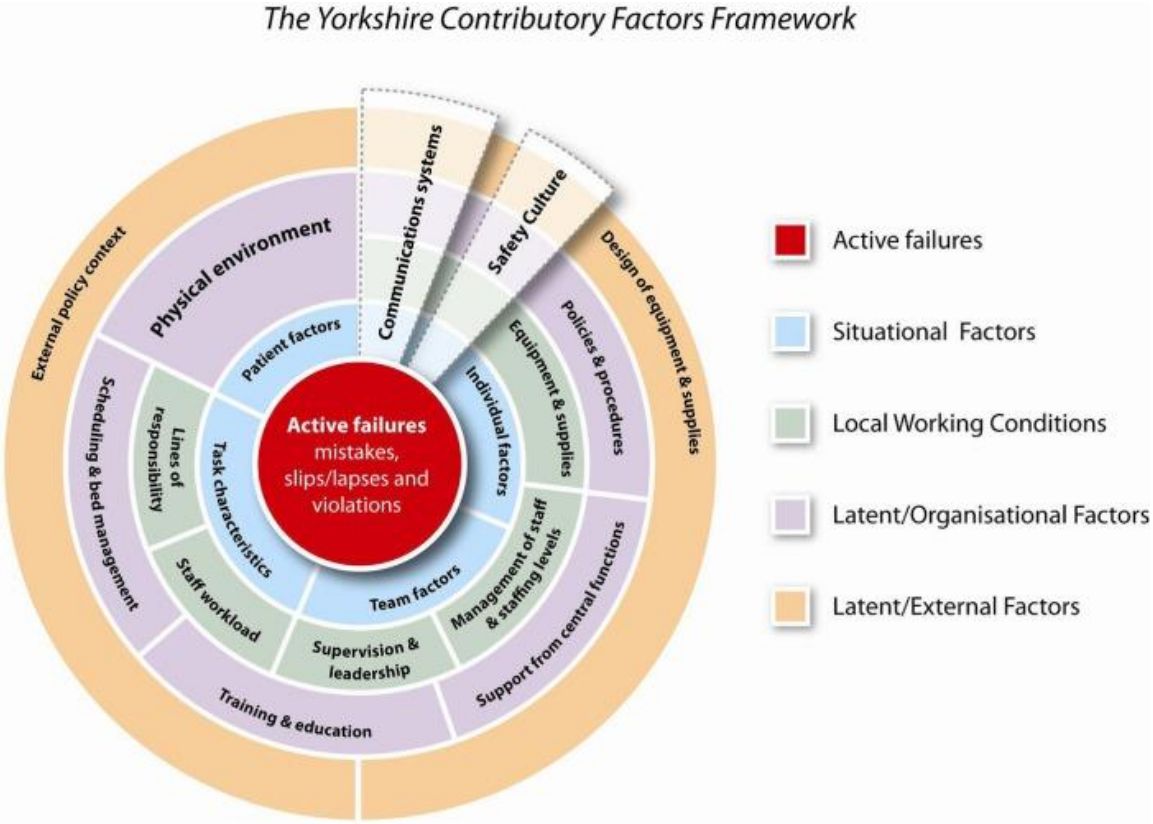
1. I confirm that I have read and understand the information sheet dated explaining the above research project and I have had the opportunity to ask questions about the project ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. ☐
3. I understand that my responses will be kept strictly confidential. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. ☐
4. I agree for the anonymised data collected from me to be used in future research done by Courtney Shaw. ☐
5. I agree to be directly quoted, anonymously, in the above research project ☐
6. I agree to be audio taped during this interview ☐
7. I agree to take part in this research project. ☐

_____	_____	_____
Name of Participant (or legal representative)	Date	Signature of participant
_____	_____	_____
Lead Researcher	Date	Signature of the Lead Researcher

Version 1.1
Dec. 27, 16

Copies:

Appendix nineteen: Yorkshire Contributory Factors Framework



Appendix twenty: Staff interview schedule

Staff starting interview prompt:

Poor experience of care

1. I'd like you to think about a time when you were caring for a patient in the emergency department who had dementia or an older person who was confused when you didn't feel you were able to provide good or safe care to that patient- or if you have ever had a patient with dementia who experienced avoidable harm while under your care, could you tell me about what happened?

2. This diagram *(show Yorkshire contributory factors framework)* shows the factors that have been shown to have an impact on patient safety. Can we go back to your story, and think about what was going on around you during that episode of care. Doing this will help me understand t he circumstances which lead to this episode of poor care happening.
    a. **Active failures** *(slips, lapses, violations)*
    b. **Situational factors** *(patient factors, individual factors, team factors, task characteristics)*
    c. **Local working conditions** *(Lines of work responsibly, workload, supervision and leadership, management of staff, staffing levels, Equipment and supplies, physical environment)*
    d. **Latent/organisational conditions** *(Policies and procedures, support from central function, training and education, scheduling and bed management, physical environment)*
    e. **Latent/ External factors** *(External policy context, design of equipement and supplies)*
    f. Communication systems
    g. Safety culture.

Good experience of care.

1) I'd like you to think about a time when you were caring for a patient in the emergency department who had dementia or an older person who was confused when you felt you were able to provide good/great and safe care to that patient- could you tell me about what happened?
2) This diagram *(show Yorkshire contributory factors framework)* shows the factors that have been shown to have an impact on patient safety. Can we go back to your story, and think about what was going on around you during that episode of care. Doing this will help me understand the circumstances which enabled you to provide great care.
    a. **Active failures** *(slips, lapses, violations)*

b. **Situational factors** *(patient factors, individual factors, team factors, task characteristics)*
c. **Local working conditions** *(Lines of work responsibly, workload, supervision and leadership, management of staff, staffing levels, Equipment and supplies, physical environment)*
d. **Latent/organisational conditions** *(Policies and procedures, support from central function, training and education, scheduling and bed management, physical environment)*
e. **Latent/ External factors** *(External policy context, design of equipement and supplies)*
f. **Communication systems**
g. **Safety culture.**

3) What information do you feel you need from your patient, or their carer, to enable you to provide good care in the emergency department?
4) What format would be best for you to get that information?
5) What is the biggest challenge you face in caring for people with dementia in the Emergency room?
6) What practices would you like to see used more frequently to improve care for people with dementia?
7) Is there anything else you would like to share with me about caring for people with dementia in the emergency department

Appendix twenty-one: Blank Data collection tool

Good care
Name:
Date:
Job:
Site
ID:

Outcome:

Situational Factors
(Patient factors, task characteristics, team factors, individual factors)

Local working conditions
(Physical environment, Lines of responsibility, staff workload, supervision and leadership, management of staff and staffing levels, equipment and supplies

Latent conditions
Organisational *(Policies and procedures, support from central functions, training and education, scheduling and management)*

External *(design of equipment and supplies, external policy context)*

Safety Culture:

Communication:

Poor care

Name:

Date:

Job:

Outcome:

Situational Factors

(Patient factors, task characteristics, team factors, individual factors)

Local working conditions

(Physical environment, Lines of responsibility, staff workload, supervision and leadership, management of staff and staffing levels, equipment and supplies

Latent conditions

Organisational (*Policies and procedures, support from central functions, training and education, scheduling and management)*

External *(design of equipment and supplies, external policy context)*

Safety Culture:

Communication:

Appendix twenty two: Patient/carer interview prompts

Carer interview

Please note, cognitive interviewing is an open ended interviewing technique which uses the participants initial narrative to shape the interview structure. As such the only question which is guaranteed is the first, the rest can only considered prompts to assist the participate expand on their story.

1) Can you tell me in your own words, about your relatives' most recent admission to hospital- in particular, the time you spent in A&E

Prompts

- *Lets go back to the start of your story, you said….can you tell me more about that*
- *…and then what happened*
- *…what were you feeling when that happened*
- *…can you think about what could see/hear happening around you at that point?*

2) Thank you for taking the time to share your story with me, is there anything else you would like to tell me about your experience of hospital, or any thoughts you would like to share about how to make the emergency department safer for people with dementia?

Appendix twenty three: HRA letter of approval

NHS
Health Research Authority

Email: hra.approval@nhs.net

Miss Courtney Shaw
University of Bradford
Health Sciences Building
Bradford
Yorkshire BD7 1DP

11 July 2017

Dear Miss Shaw

Letter of HRA Approval

Study title:	**Optimizing the transition from home to hospital: Improving the quality and safety of care in A&E for people with Dementia**
IRAS project ID:	**219697**
REC reference:	**17/EE/0227**
Sponsor:	**University of Bradford**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *"After Ethical Review – guidance for sponsors and investigators"*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

Your IRAS project ID is **219697**. Please quote this on all correspondence.

Yours sincerely

Simon Connolly
Senior Assessor

Email: hra.approval@nhs.net

Copy to: *Miss Tamsin Holt, University of Bradford [Sponsor]*
Mr Graham Halls, Portsmouth Hospitals NHS Trust [Lead NHS R&D]

Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Recruitment flier]	1.2	19 June 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance]		29 July 2016
Interview schedules or topic guides for participants [Staff interviews]	1.1	25 March 2017
Interview schedules or topic guides for participants [Carer interview prompts]	1.1	24 May 2017
Interview schedules or topic guides for participants [Person with dementia interview]	1.1	25 May 2017
Interview schedules or topic guides for participants [Focus group topic guides]	1.1	25 May 2017
IRAS Application Form [IRAS_Form_25052017]		25 May 2017
Letter from funder [Award letter]		28 January 2015
Letter from sponsor [Studentship letter]		16 October 2016
Letters of invitation to participant [E-mail contact template]	1.1	25 May 2017
Other [Notice of Observations]	1.1	24 May 2017
Other [Participant handout-supportive resources]	1.1	25 March 2017
Other [Contact form]	1.1	25 March 2017
Other [Statement of Activities - Hampshire Hospitals NHSFT]	1	26 June 2017
Other [Statement of Activities - Portsmouth Hospitals NHST]	1	26 June 2017
Other [Statement of Activities - South Central Ambulance Service NHSFT]	1	26 June 2017
Other [Schedule of Events - Hampshire Hospitals NHSFT]	1	26 June 2017
Other [Schedule of Events - Portsmouth Hospitals NHST]	1	26 June 2017
Other [Schedule of Events - South Central Ambulance Service NHSFT]	1	26 June 2017
Other [Ethics amendments made]		23 June 2017
Participant consent form [Consultee form]	1.1	27 December 2016
Participant consent form [Certificate of consent]	1.4	07 July 2017
Participant information sheet (PIS) [Person with dementia RHCH]	1.3	07 July 2017
Participant information sheet (PIS) [Person with dementia QAH]	1.3	07 July 2017
Participant information sheet (PIS) [RHCH PIS carer]	1.3	07 July 2017
Participant information sheet (PIS) [PIS QAH carer]	1.3	07 July 2017
Participant information sheet (PIS) [QAH information consultee]	1.3	07 July 2017
Participant information sheet (PIS) [PIS RHCH consultee]	1.3	07 July 2017
Participant information sheet (PIS) [RHCH staff information]	1.3	07 July 2017
Participant information sheet (PIS) [QAH information staff]	1.3	07 July 2017
Referee's report or other scientific critique report [peer review feedback]		
Research protocol or project proposal [Protocol]	1.3	23 January 2017
Summary CV for Chief Investigator (CI) [CI resume]	1.1	10 May 2017
Summary CV for student [CS CV]	1.1	10 May 2017
Summary CV for supervisor (student research) [GA CV]		10 May 2017
Summary CV for supervisor (student research) [AC CV]		24 May 2017

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Courtney Shaw
Email: c.j.shaw@bradford.ac.uk

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/ consent documents and consent process	Yes	Participant information for the focus groups has yet to be finalised. An amendment will be submitted with the final documents prior to this component of the study commencing.
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	Statements of Activities and Schedules of Events will be used with participating NHS organisations. Exchange of the Statement of Activities will confirm the capacity and capability of an organisation to host the research.
4.2	Insurance/ indemnity arrangements assessed	Yes	Insurance for the management and design of the study is provided by the sponsor, and indemnity for the

Section	HRA Assessment Criteria	Compliant with Standards	Comments
			conduct by the NHS. Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study
4.3	Financial arrangements assessed	Yes	External study funding has been secured from the Alzheimer's Society. Funding is not available to participating NHS organisations.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	Mental Capacity Act: arrangements for the identification of personal consultees are clear. The study has been reviewed by an appropriately flagged research ethics committee.
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	The study has a favourable ethical opinion from the East of England - Cambridge Central Research Ethics Committee.
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

There are two kinds of participating NHS organisations:

- Full research sites, at which all research activities as described in the protocol and IRAS form will be conducted
- Staff only sites, at which only research activities involving NHS staff will be conducted, where there is no patient participant contact or recruitment.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

Participating NHS organisations in England **will be expected to formally confirm their capacity and capability to host this research**.

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capacity will be confirmed is detailed in the *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* section of this appendix.
- The Assessing, Arranging, and Confirming document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).
A Principal Investigator will be in place at participating NHS organisations and the applicant has already identified suitable individuals. GCP training is not a generic training expectation, in line with the HRA statement on training expectations.

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken
University researchers would be expected to obtain a Letter of Access from participating NHS organisations. This would be on the basis of a Research Passport, confirming a standard DBS check and occupational health clearance.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.
• The applicant has indicated that they intend to apply for inclusion on the NIHR CRN Portfolio. • The focus group / PPI activity will not commence until an amendment has been submitted finalising the participant information and arrangements for conducting this component of the study. This is because the results of the first part of the study will inform this work.

Appendix twenty four: 'Wish list'

Physical Space

- Separate unit for older people
- Designated observable area- with more opportunities for interaction
- More, and better, chairs
- A Dementia friendly area
    - Pictures
    - Calming colours
    - Quieter
    - Dimmable lights
- Safer room
    - More padding
    - Lower bed
    - Bigger rooms
    - Calmer rooms.
- More arm chairs
- More tables would be good
- More clocks
- Better ability to regulate night and day
- An area to sit safely.
- More accessible toilets
- Better ability to regulate night and day
- Easily accessible kettle and fridge

Communication

- Access to community and GP records
- RESPECT forms
- This is me
- Anything that will help improve communication- glasses, hearing aids, dentures- should be brought in

Supplies

Entertainment

- More access to games, touching/feeling/ interactive things/ entertainment
- Anything to keep people from wanting to wander
- Books or distraction things, magazines. Occupiers
- Access to stimulation things- its good, make it better!
- Massive fish tube- like a lava lamp but with fish
- Cards, colouring books, a CD player for some old music
- Rummage boxes
- Earmuffs to reduce noise?

Medical supplies

- More equipment (machines ect) would help so staff don't have to hunt for, or wait for, required equipment.
- More cups and beakers- they keep disappearing
- Longer gloves
- More food options.
- More non-slip slippers
- Availability of adaptive equipment to support nutrition and hydration, more beakers, better cups, to encourage independent eating and drinking
- More moving and handling equipment- to encourage independence.

Staffing and care processes

- An out of hours care assistant on call with dementia training
- A dementia nurse in ED- Not just a staff member who is trained, but super-numeric
- Better training so staff can treat patients with dementia with compassion.
- We could use the dementia team in A&E more
- More staff
- Dementia trained volunteers-"a lot of time what patients with dementia is time- we don't have that in A&E".
- Better training on how to deal with common problems like aggression, distress, hallucinations, delirium, wandering, and de-escalation
- More skills based training
- Better streaming of patients with dementia or frailty
- Mandatory screening for cognitive impairment for those over 65 at the front door

External resource

- Better access to, and integration with, community resources- makes it easier to turn around patients and get them home
- Better transport- especially out of hours
- For people to come in with their own clothes/ a change of clothes/ information about personal preferences
- Transport to get people home later in the evenings
- Money for social care to keep people out of the hospital
- Better training opportunities for "silver trauma"

Appendix twenty five: Co-design recruitment poster

Who: I am seeking volunteers who are living with dementia, or supporting someone living with dementia, to participate in a patient and public involvement event to help answer the question…

What is important to people living with dementia when they receive care in A&E?

When: Friday May 4th, 2018.
Start time **10am**
Finish time **3pm.**
Lunch will be provided.

What is involved?

- On this day, you will be asked to share your opinions on what is important to people who are living with dementia when they receive care in A&E.
- In the morning we will brainstorm together and share our experiences in small groups.
- After a lunch break, we will work together to create a statement that highlights the priorities of people with dementia.
- These statements will be used as part of a doctoral research project, and may be used to inform proposals for changes to the health system in the future.

Where: The University of Bradford, Bright Building, Richmond Road, Bradford BD71DP

The University of Bradford appreciates and values the contribution of those who volunteer their time and expertise. A small honorarium will be provided to those who participate.

For more information please contact Courtney Shaw at C.J.Shaw@bradford.ac.uk or on 07415827558

Appendix twenty six: What is a Dementia Friendly Emergency Department

In a Dementia Friendly Emergency Department;

- People with dementia are treated with compassion, dignity and respect.
- Staff members have training in dementia, which they use to provide care that is person centered. Staff adapt their approach to ensure it is suitable to the needs and abilities of the individual
- The impact of dementia on cognitive ability (*such as memory and processing*) and behaviour is understood. Adjustments are made to support the person with dementia.
- Staff uses appropriate language when interacting with people with dementia and their carers.
    - Language that is non-stigmatizing
    - Language that is easy to understand
- Information about care processes, diagnosis, and future plans are communicated to the patient and carer accurately and in a timely manner
- The physical space is safe and comfortable for people with dementia
    - There is a quiet or quieter space available
    - There are facilities which enable and support a carer to stay comfortably
    - There is easy access to food and drinks
- If the person with dementia attends with a carer;
    - The experience and expertise of the carer is recognised and acknowledged.
    - Staff commit to creating partnerships of care where the carer is a respected member of the care team and supported to stay involved in ways they are comfortable with.
    - The potential emotional strain of caring is recognised, and the needs of the carer are considered as part of the care planning process